

**QUALITY OF LIFE OF PEOPLE WITH DEMENTIA
AND THEIR
INFORMAL CAREGIVERS**

—

A CLINICAL AND ECONOMIC ANALYSIS IN NEW ZEALAND

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The material presented in this thesis is the original work of the candidate except as acknowledged in the text, and has not been previously submitted, either in part or in whole, for a degree at this or any other University.

Franziska Gallrach

This thesis is dedicated to my grandmother, Charlotte, and to my mum, Carola.

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Abstract

Background

Multivariate analyses of quality of life (QoL) in dementia are relatively rare. This study was the first aiming to measure QoL of persons with dementia and their informal caregivers in New Zealand. To date, it is also the only study examining what interventions from primary and secondary care in New Zealand are helpful for enhancing QoL and what these interventions cost.

Methods

In this prospective cohort study, questionnaires (including the Quality of Life-Alzheimer's Disease Scale and the Neuropsychiatric Inventory) investigating various QoL-domains were administered to 53 outpatients of a memory clinic recently diagnosed with dementia, and their caregivers at baseline and 12-month follow-up. Time and resource utilisation were assessed in order to identify direct and indirect costs using questionnaires and diaries (over 12 months).

Results

Cognition scores of persons with dementia (PWDs) ranged from 49 to 91 on the Modified-Mini-Mental State Examination (3MS); scores on the Clinical Dementia Rating Scale (CDR) ranged from 0.5 to 3, with 83% of PWDs being in the early stages of the illness at baseline ($CDR \leq 1$).

Most PWD measurements confirmed the predicted correlations including a strong link between PWDs' and caregivers' QoL. Many correlations remained stable over 12 months. Combined information and support interventions achieved significantly better PWD and caregiver QoL than single interventions. Direct costs (including costs of informal caregiving time) increased with an increase in dementia severity, neuropsychiatric and behavioural symptoms and functional limitations. There was a clear trend that caregivers were more distressed if patients received less in-home support. Direct non-medical costs of PWDs living at home did not increase with the severity of PWDs' cognitive impairment. In 2008/09, there were an estimated 1,896 persons in

Canterbury providing a total of 5.47 million hours of care for PWDs. This unpaid care had a value of NZ \$135.8 million. Caregivers were much more likely to be depressed if they had a low income. More than one-third of family-caregivers (39.5%) thought that financial compensation for their time spent caring would enable them to look after the PWD at home for longer.

Conclusions

A mix of different clinical and non-clinical (including economic) factors can predict QoL in dementia. The strong link between PWDs' and caregivers' QoL calls for a systemic approach in dementia care. QoL can be sustained over 1 year in a cohort of mainly early dementia patients and their informal caregivers. Developing psychosocial and financial incentives could be a key factor to support PWDs and their informal caregivers in New Zealand, consequently enabling them to live in the community for longer. These outcomes also have implications for health professionals and social policy makers which must be addressed as health practitioners and the wider community strive both for best practice and for cost-effective care of our increasingly ageing population.

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Published abstracts arising from this thesis

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1 Introduction

The author has taken a snapshot approach introducing key issues related to the clinical and economic burden of dementia around the world and particularly in New Zealand.

- Dementia and Alzheimer's disease (AD) in particular is one of the most common diseases of old age (Bachman, et al., 1992; Brookmeyer, Gray, & Kawas, 1998; Launer, et al., 1999). However, Alzheimer's and related dementias are not part of the normal aging process.
- Dementia poses an enormous health and economic burden on society. This burden will increase dramatically during the next 20 years due to the changing structure of society (Logsdon, Gibbons, McCurry, & Teri, 2002).
- Alzheimer's Disease International estimated that there were 30 million people with dementia worldwide in 2008, with 4.6 million new cases every year (Alzheimer's Disease International & Prince, 2008). The organisation further predicted that "the number of people affected will be over 100 million by 2050" (p. 1).
- "The total worldwide societal cost of dementia, on the basis of a dementia population of 29.3 million persons, was estimated to be US \$315.4 billion in 2005, including US \$105 billion for informal care (33%)" (Wimo, Winblad, & Jonsson, 2007).
- In 2005, more than three quarters (77%) of the total costs occurred in the more developed regions. However, these regions account for less than half (46%) of the worldwide prevalence of dementia (Wimo, et al., 2007).
- The number of people with dementia in the Asia Pacific region will increase from 13.7 million persons in 2005 to 64.6 million by 2050 (Access Economics, 2006).
- In New Zealand, the number of people affected by dementia will rise from 41,000 in 2008 to 75,000 in 2026 (Access Economics, 2008).
- Even though different studies might find slightly different prevalence rates and therefore predict slightly different numbers of people likely to suffer from dementia in the future, the dementia epidemic is certain because the risk for dementia increases with increasing age and therefore with an ageing society (Hendrie, 1998; Paykel, et al., 1994).

- The percentage of people aged 60 years and older in the Asia Pacific region will grow from under 10% in 2006 to 25% of the total population by 2050 (Access Economics, 2006).
- In Canterbury, the proportion of older people will increase from 13% to 20% of the total Canterbury District Health Board population by 2021 (Canterbury District Health Board, 2004).
- Apart from the number of people with dementia, other factors also drive the social and economic impact of the disease: urbanisation, trends away from extended families, and the increasing number of elderly people who therefore live alone. The ability to care for these people will greatly depend on a mix of formal and informal care giving.
- With an estimated 12,333 new cases of dementia being diagnosed each year, the dementia prevalence will increase from 1.0% of the New Zealand population in 2008 to 2.7% in 2050 (Access Economics, 2008).
- Most people with dementia receive care at home, generally provided by a female caregiver, usually a spouse or daughter (Access Economics, 2006).
- Caregivers are crucial for maintaining people affected with dementia in the community. Without a caregiver, or when a caregiver is stressed, the likelihood of nursing home admission rises sharply (Brodaty, McGilchrist, Harris, & al., 1993).
- Caregivers can experience adverse psychological, physical, social, and financial consequences (Brodaty, Green, & Koschera, 2003).
- There is no cure yet for Alzheimer's and related dementias. Therefore, quality of life (QoL) has become the focus of dementia care in the past decade.
- There are virtually no New Zealand data regarding the impact of dementia on patients' and informal caregivers' QoL or the formal care supports available and their ability to sustain QoL in dementia. Moreover, due to the lack of national data, the recent economic report on the costs of dementia in New Zealand had to be based in many aspects on estimates derived from overseas data (Access Economics, 2008).
- To date, multivariate analyses of quality of life in dementia are relatively rare (Banerjee, et al., 2009).

It follows an outline of the clinical definitions of different dementias, of risk and protective factors (1.1.4, p. 7), of prevention and treatment strategies (1.1.5, p. 7), as well as an overview of support options available in New Zealand (1.1.6, p. 11) and of the economic impact of dementia in New Zealand (1.1.7, p. 13).

1.1 Dementia

The World Health Organization (WHO) (2007) defines dementia as:

... a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.

Depending on the cause of illness, three groups of dementias can be distinguished:

1. Dementias, caused by degenerative changes of the brain tissue – **neurodegenerative dementias**, such as Alzheimer's dementia (AD), Lewy bodies dementia (LBD) or Frontotemporal dementia (FTD);
2. Dementias where damaged or narrow arteries cause lack of blood and damage to the body's circulatory system including the brain, for example after multiple strokes – **vascular dementias** (VD);
3. Dementias which are present during the progression of another illness such as Creutzfeldt-Jacob disease or HIV – **secondary dementias**.

There are more than 100 known causes of dementia (World Health Organization, 2006). For the purpose of this current study, the focus was Alzheimer's, vascular and mixed dementia. In a recent

report, the American Alzheimer's Society defined mild cognitive impairment (MCI) which differs from dementia (Alzheimer's Association, 2009b):

Mild cognitive impairment (MCI) is a condition in which a person has problems with memory, language, or another essential cognitive function that are severe enough to be noticeable to others and show up on tests, but not severe enough to interfere with daily life. Some people with MCI go on to develop dementia. For others, the symptoms of MCI do not progress to dementia, and some people who have MCI at one point in time later revert to normal cognitive status. (p. 235)

Dementia is characterised by (Access Economics, 2008):

- cognitive impairment (memory loss, speech/language/naming difficulties, confusion ...);
- neuropsychiatric and behavioural symptoms (hallucination, delusion, depression, agitation, apathy...);
- impairment of daily living activities (difficulties with showering, eating, grocery shopping, geographic and temporal orientation, dressing, performing household tasks ...).

1.1.1 Alzheimer's dementia

Alzheimer's is the most common form of dementia, estimated to account for 50 – 70% of all dementias (World Health Organization, 2006) often resulting in:

- memory loss,
- difficulties performing familiar tasks,
- problems with language,
- disorientation,
- decreased judgment,
- changes in personality and/or
- loss of initiative.

AD is diagnosed by excluding any other possible cause for the symptoms. Only then, is a clinical

diagnosis of probable AD given. The diagnosis can only be confirmed with 100% certainty through a neuro-pathological post-mortem examination.

AD was first described by Alois Alzheimer in 1906. Initially, dementias were differentiated into senile and presenile depending on if a person's symptoms started when they were aged 65 or older. However, this distinction is less common nowadays since the symptoms of dementia do not change depending on the patient age. Unlike other dementias, the onset of Alzheimer's is often gradual. AD is a progressive dementia "that gets worse over time, gradually interfering with more and more cognitive abilities" (Bartlett, Gray, Byrne, Travers, & Lui, 2007).

AD affects different people in different ways, at different times. According to Bartlett, et al. (2007), the illness "usually begins with episodic memory impairment and encompasses language, visuospatial and behavioural dysfunction" (p. 13). At an early stage, persons with dementia (PWDs) usually have difficulties learning and recalling new information. With illness progression, PWDs can also experience "confusion, disorganized thinking, impaired judgment, trouble expressing themselves, and disorientation with regard to time, space, and location, which may lead to unsafe wandering and socially inappropriate behavior" (Alzheimer's Association, 2009b). In the more advanced stages of AD, "people need help bathing, dressing, using the bathroom, eating, and carrying out other daily activities" (Alzheimer's Association, 2009b). In the final stages of the disease, PWDs often lose their ability to communicate and to walk and they become bedbound and incontinent. At this point PWDs are reliant on constant care and supervision, "often dying from dementia/failure to thrive or from coronary heart disease" (Bartlett, et al., 2007). **Table 1** shows the Clinical Dementia Rating (CDR) scale, an instrument widely used to stage the severity of dementia, ranging from 0.5 points (questionable dementia) to 1 point (mild), 2 points (moderate) and 3 points (severe dementia).

Table 1: Clinical Dementia Rating (CDR) scale¹

	Impairment				
	None 0	Questionable 0.5	Mild 1	Moderate 2	Severe 3
Memory	No memory loss or slight inconsistent forgetfulness	Consistent slight forgetfulness; partial recollection of events; "benign" forgetfulness	Moderate memory loss; more marked for recent events; defect interferes with everyday activities	Severe memory loss; only highly learned material retained; new material rapidly lost	Severe memory loss; only fragments remain
Orientation	Fully oriented	Fully oriented except for slight difficulty with time relationships	Moderate difficulty with time relationships; oriented for place at examination; may have geographic disorientation elsewhere	Severe difficulty with time relationships; usually disoriented to time, often to place	Oriented to person only
Judgment & Problem Solving	Solves everyday problems & handles business & financial affairs well; judgment good in relation to past performance	Slight impairment in solving problems, similarities, and differences	Moderate difficulty in handling problems, similarities, and differences; social judgment usually maintained	Severely impaired in handling problems, similarities, and differences; social judgment usually impaired	Unable to make judgments or solve problems
Community Affairs	Independent function at usual level in job, shopping, volunteer and social groups	Slight impairment in these activities	Unable to function independently at these activities although may still be engaged in some; appears normal to casual inspection	No pretense of independent function outside home Appears well enough to be taken to functions outside a family home	Appears too ill to be taken to functions outside a family home
Home and Hobbies	Life at home, hobbies, and intellectual interests well maintained	Life at home, hobbies, and intellectual interests slightly impaired	Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interests abandoned	Only simple chores preserved; very restricted interests, poorly maintained	No significant function in home
Personal Care	Fully capable of self-care		Needs prompting	Requires assistance in dressing, hygiene, keeping of personal effects	Requires much help with personal care; frequent incontinence

Score only as decline from previous usual level due to cognitive loss, not impairment due to other factors.

It has been estimated that on average 7.1 years pass from the onset of the first clinical symptoms until death (Bartlett, et al., 2007) but, according to a recent report (Access Economics, 2008), the illness can last for "3 – 20 years from diagnosis, depending on age of onset" (p. 1).

1.1.2 Vascular dementia

Bartlett, et al. (2007) defined vascular dementia as an illness "caused by cerebrovascular conditions including multi-infarct disease and stroke" (p. 11). The onset is often sudden following a stroke but can be gradual. Vascular dementia is considered the second most common form of dementia accounting for 20-30% of cases (Access Economics, 2008; Alzheimer's Association, 2009b). "Symptoms often overlap with Alzheimer's, although memory may not be as seriously affected" (Alzheimer's Association, 2009b). The illness is progressive, but the decline can be less steady than in AD, resulting more often in 'good and bad days/periods'.

¹ Reproduced from Morris (1993) by the Alzheimer's Disease Research Center at Washington University in St. Louis (2006).

1.1.3 Mixed dementia

Mixed dementia is defined as the coexistence of Alzheimer's and another type of dementia, most commonly vascular dementia, but also other types such as dementia with Lewy bodies (Alzheimer's Association, 2009b).

1.1.4 Risk and protective factors

Only some factors have been identified as definite risk factors for dementia (Bartlett, et al., 2007). Older age is the most significant risk factor. Dementia increases in prevalence from 1 in 1,000 for people aged less than 65 years to nearly 25% for people aged 85 years and over (Access Economics, 2008). A number of genetic risk factors have been discovered including a family history of AD, Down Syndrome and stroke, with the gene Apolipoprotein E (ApoE) increasing the risk of developing AD but not causing it (Access Economics, 2006; Bartlett, et al., 2007). However, the significance of these factors varies depending on a number of other risk and protective factors prevalent. These environmental factors are not understood entirely and are therefore not definite risk factors, but they have been associated with an increased risk to develop dementia including an earlier severe head trauma, depression, hypertension, diabetes mellitus, exposure to toxins such as pesticides, alcohol abuse and obesity (Bartlett, et al., 2007).

A number of strategies have been identified which probably have a protective function against developing dementia: high education and intelligence, moderate alcohol intake, and a physically, socially and cognitively active lifestyle throughout middle-age (Bartlett, et al., 2007). Other factors might also be protective against dementia including cholesterol lowering medication, non-steroidal anti-inflammatory medications, aspirin and Omega-3 fatty acids such as oily fish (Bartlett, et al., 2007). The research is inconclusive regarding the following factors: gender, regional variation, smoking and hormone replacement therapy (Bartlett, et al., 2007).

1.1.5 Prevention and treatment strategies

Neither pharmacological nor non-pharmacological treatments can cure dementia at present. However, risk factors can be reduced, the behavioural and psychological signs and symptoms of

dementia managed and/or, and quality of life for the person and their family-caregivers improved (Access Economics, 2008):

1. **Prevention** includes elimination or postponement of onset till later in life by addressing contributing medical or psychological factors such as head trauma or cardiovascular disease and its risk factors (smoking, diet, physical activity, overweight and obesity, hypertension, high cholesterol). Recent developments in neuroscience, genetic and medical technology suggest that prevention in terms of slowing the progression of dementia is possible, although there is a need for further research and, in particular, large randomised prevention trials. If any of these or other future prevention strategies could delay the onset of dementia even modestly, the total years of disabled life may be significantly reduced, with associated substantial public health resource allocation implications.
2. **Early diagnosis/intervention:** Improved diagnosis is now possible through new neuroimaging technologies. Early diagnosis means the person and the family benefit from drug treatments, support and planning strategies. This helps those involved have more control over the disease and their lives and can slow progression due to early access to pharmacotherapies. Financial and legal plans can be made, with the full agreement of the person with dementia. The individual and family can adjust better to the diagnosis, understand the illness and learn how to cope better through adequate counselling and education, remaining productive longer and improving quality of life.
3. **Psychosocial approaches** including support, counselling, education and memory loss programs through all stages of dementia progression can be very helpful for the individual and the family. Psycho-education can help the person and their family learn to manage certain symptoms – such as cognitive behaviour therapy – and can help prevent secondary morbidity such as depression or anxiety in the

person with dementia and/or their family members. Organisations such as Alzheimers New Zealand are important networks for the provision of such support and information services.

4. **Medications** (pharmaceutical and natural) are used to treat cognitive decline and memory loss. The cholinesterase inhibitors work best in the mild to moderate stages of Alzheimer's disease and there is growing evidence they may be effective in other forms of dementia. They improve clarity of thought, ADL functionality, mood and behaviour. They may have (mild) side effects, however, and they cannot so far reverse progression. Other drugs are used to prevent and slow dementia – for example, aspirin and blood-thinning agents to reduce risk of (further) stroke, memantine, secretases, anti-oxidants (prescription and over-the-counter, such as ginkgo biloba and fish oils).
5. **Medical and surgical interventions:** People with dementia may receive care from their primary care provider (general practitioner or GP) as well as from specialist neurologists, psycho-geriatricians, psychiatrists, physicians in geriatric medicine and other consultant physicians. The GP plays a key long-term role from diagnosis to death, while specialists are important for periodic neuropsychological assessments and pharmaceutical management. Two controversial potential surgeries are in the experimental stage, a shunt for cerebrospinal fluid and more radical omentum transplantation.
6. **Allied health, community and residential care services** encompass a broad range of services for people with dementia and their family carers. In allied health, there are physical (such as swimming, hydrotherapy, massage), occupational and speech-language therapies that can assist with specific problems (such as appropriate home modifications), as well as diversional, reminiscence, validation, music, movement/dance and craft therapies. Community care services include a

range of nursing, personal care and domestic home help services (such as meals, shopping, cleaning and home maintenance), as well as respite care. Residential care ideally provides a full spectrum of such services including dementia-specific services.

7. **Promoting an understanding of what is quality dementia care** features of quality person-centred care include the need to:

- *redefine problems and understand behaviours* of people with dementia – that is, focus on the person and not just target the behaviours;
- plan and implement specialised *activity programs* – to stimulate interest and encourage activities designed to address specific psychosocial needs and preferences;
- *personalise the care* – emphasising intimate knowledge of who the person is – their history, family connections, values and current circumstances;
- *give carers ownership and care responsibility* – build relationships by subdividing large numbers of care recipients into small working groups, for whom designated carers are responsible;
- *create domestically scaled social environments* – clustered residential designs, with kitchen-dining focus areas, have been successful in creating a homelike environment and building social interactions in residential care services;
- *provide flexibility of care routines and practices* – a relaxed organisational environment using strategies that focus on timing, routines and needs, preventing resistive responses;
- *cultivate professionalism of care and support of caregivers* – create a culture of doing something innovative, progressive and worthwhile, rather than a task oriented completion of jobs' approach;

- *include relatives in the life and care of the resident* – expend effort to maintain continuity in the person's life through encouraging ongoing contact with family and others who can provide undivided personal attention. (pp. 6 - 8)

1.1.6 Care and support for people with dementia and their families in New Zealand

With an estimated 12,333 new cases of dementia being diagnosed each year, the dementia prevalence is predicted to increase from 1.0% of the New Zealand population in 2008 to 2.7% in 2050 (Access Economics, 2008). According to the Canterbury District Health Board (CDHB) (2004), there are no accurate data available on the incidence and prevalence of dementia in Christchurch and Canterbury (p. 126). However, the census data from 2006 show that there were 521,832 people living in Canterbury with 13.9% ($n = 72,615$) older than 65 years of age (Statistics New Zealand, 2006b). It is estimated that 1% of the New Zealand population has dementia (Access Economics, 2008) which means that **there are an estimated 5,218 persons with dementia in Canterbury.**

The ability to care for these people will greatly depend on a mix of formal and informal caregiving. Most people with dementia receive care at home, generally provided by a female caregiver, usually a spouse or daughter (Access Economics, 2006). Caregivers are crucial for maintaining people affected with dementia in the community. Without a caregiver, or when a caregiver is stressed, the likelihood of nursing home admission rises sharply (Brodaty, et al., 1993). However, caregivers can experience adverse psychological, physical, social, and financial consequences (Brodaty, et al., 2003).

There are two major documents which set the policy framework for dementia care in New Zealand: first, the Health of Older People Strategy (Ministry of Health, 2002) and second, the Positive Ageing Strategy which “reinforces Government's commitment to promote the value and participation of older people in communities” (Ministry of Social Development, 2001). The Health of Older People Strategy consists of eight objectives, some of which specifically focus on PWDs

and their family-caregivers. For example, the third objective on access to care states that “funding and service delivery will promote timely access to quality integrated health and disability support services for older people, family, whānau and carers” (p. 27). More specifically, the “Ministry will develop a service development plan for older people with dementia” (p. 30). The sixth objective emphasises the need for early diagnosis and intervention whereas the eighth objective outlines the plans to support ageing in place (Ministry of Health, 2002). It highlights that the support for family, whānau and other caregivers is a key component in reaching this goal (p. 60). The only governmental dementia-specific document is more than a decade old and in urgent need of an update, the “Guidelines for the support and management of people with dementia” (Ministry of Health, 1997).

Similar to other western countries, there are a number of support options and services available in New Zealand once a person has been diagnosed with dementia including (Alzheimers New Zealand, 2009):

- local Alzheimer’s organisations,
- social workers,
- counsellors,
- GPs,
- personal and domestic in-home help,
- meals-on-wheels,
- day-care,
- short-term respite care.

In order to access certain support services, PWDs have to receive a needs assessment to determine the level of care necessary since many services are covered or subsidised by the government.

The clinical burden of dementia results in an economic burden for society as well as for individuals affected by dementia and their families. Therefore, the economic burden of dementia in New Zealand is discussed next.

1.1.7 The economic impact of dementia

“The total worldwide societal cost of dementia, on the basis of a dementia population of 29.3 million persons, was estimated to be US \$315.4 billion in 2005, including US \$105 billion for informal care (33%)” (Wimo, et al., 2007). In 2005, more than three quarters (77%) of the total costs occurred in the more developed regions which account for less than half (46%) of the worldwide dementia prevalence (Wimo, et al., 2007). In New Zealand, the total financial costs of dementia were an estimated NZ \$712.9 million in 2008 (Access Economics, 2008). **Figure 1**, which is reproduced from the ‘Economic impact of dementia in New Zealand’ report shows how the financial costs were distributed in 2008 in New Zealand (Access Economics, 2008).

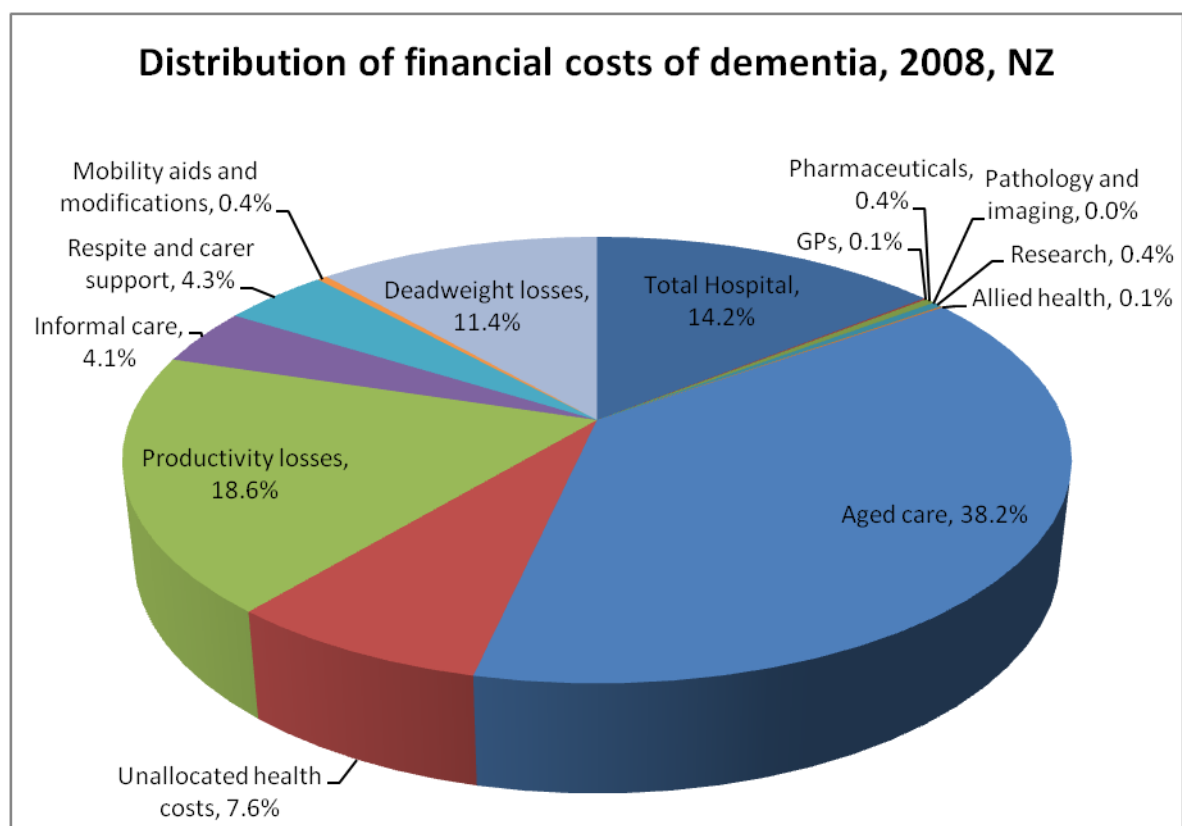


Figure 1: Distribution of financial costs of dementia in New Zealand in 2008.

Note. Reproduced from the ‘Economic impact of dementia in New Zealand’ report (Access Economics, 2008) (p. iv).

In the economic report (Access Economics, 2008), the actual costs for each health system factor are listed (p. v). The biggest cost factor was aged residential care at NZ \$272.5 million in 2008. Costs for hospital care were also considerable, at NZ \$100.9 million, which includes NZ \$92 million inpatient costs and NZ \$8.8 million private inpatient and outpatient costs. Costs for

pharmaceuticals and research totalled around NZ \$2.9 million each. “Overhead costs of administering health systems, capital expenditures, public health programs were an estimated \$54.5 million, with GPs, allied health, pathology and imaging each under \$1 million per annum” (p. v).

These costs were calculated by including only the additional expenditures on PWDs in comparison with persons of the same age and gender (Access Economics, 2008). Productivity costs included PWDs’ lower employment participation (NZ \$124.7 million), higher rates of absenteeism (NZ \$2.3 million) and “the loss of human capital as a result of premature mortality (NZ \$5.5 million)” (p. v). Using the conservative opportunity cost method (caregivers participate less in the workforce), the value of their informal care was estimated at NZ \$29.3 million. However, using the wage replacement method (replacing the informal caregiver with an outsourced person providing the same care on an hourly rate), the value of care provided unpaid by family and friends was NZ \$402.1 million (Access Economics, 2008). Expenditures for respite and support services were estimated at NZ \$30.9 million and the “deadweight efficiency losses from welfare transfers, government expenditures and taxation revenues forgone” at NZ \$81.3 million (p. v). Of all financial costs, 62.6% were paid for by the government, 30.6% by individuals and 6.8% by others in society (Access Economics, 2008). Using the concept of Disability Adjusted Life Years (DALYs), it was estimated that non-financial costs due to the loss of well-being and quality of life, and due to premature deaths from dementia totalled NZ \$9.04 billion in 2008, “more than 12 times the financial costs” (p. vi).

The most effective way to generate savings would be if the onset of dementia could be delayed or incidence reduced through prevention. Studies have indicated that relatively small delays in the onset and progression of dementia could substantially reduce disease-related costs (Access Economics, 2006; Brookmeyer, et al., 1998). Many psychosocial and pharmacological/diagnostic interventions have been shown to be cost-effective (Brodaty, et al., 2003; Clegg, et al., 2002). Nevertheless, most studies focus on medications. For example, cholinesterase inhibitors can help

to slow down the progression of AD symptoms for 9 to 12 months and possibly longer although they do not reverse disease or prolong life (Lopez, et al., 2002). Economic studies have shown that these pharmacotherapies may have three important impacts: delay the admittance into permanent care of a PWD, reducing the number of hours of informal care giving, and improving the QoL of people with dementia and their caregivers (Access Economics, 2006). Yet early access to medications at an affordable price was a major constraint in New Zealand for PWDs and their caregivers at the time this current study was conducted (Access Economics, 2008).

The drugs donepezil, rivastagmine and galantamine are all available in New Zealand for the treatment of mild to moderate dementia. However, these medications are not subsidised. To be subsidised a drug needs to be listed by PHARMAC, the Pharmaceutical Management Agency of New Zealand. PHARMAC's point of view, not to recommend these drugs for subsidising, has not shifted in the past decade and a personal email communication between PHARMAC and the primary investigator can be found in Appendix V (p. 432). The average monthly costs for these drugs were NZ \$230.00 until late 2009 when the patent for donepezil ran out and the first generic version became available at an approximately 50% lower price than the branded product (Alzheimers New Zealand, 2009). As a result, PHARMAC is now proposing to subsidise this new generic version which could be available in July 2010 at a subsidised retail price of NZ \$7.71/14.06 (PHARMAC, 2010). Nevertheless, according to PHARMAC's proposal, the treatment would be limited to persons with mild to moderate AD who live in the community and have adequate support. After an initial 6 month approval period, the treatment would be reviewed and only continued if "the patient has demonstrated a significant and sustained benefit from treatment" (p. 2).

In addition to the benefits of medical interventions, some studies also have shown cost-effectiveness of interventions for caregiver education, training and support. A meta-analysis of 34 psychosocial interventions for caregivers of people with dementia (from 30 studies) indicated significant benefits in caregiver psychological distress, caregiver knowledge of the disease, and

patient mood. The authors concluded that some caregiver interventions can reduce caregiver psychological morbidity and help demented people stay at home longer (Brodaty, et al., 2003). Other studies showed that caregiver counselling and support reduced the rate of nursing home placements of AD patients and also improved caregivers' satisfaction with social support, response to patients' behaviour problems, and symptoms of depression (Mittelman, 2003; Mittelman, Haley, Clay, & Roth, 2006; Mittelman, Roth, Coon, & Haley, 2004).

During the time this current study was conducted, Statistics New Zealand commissioned the General Social Survey of 2008 (Statistics New Zealand, 2009a), the Household Economic Survey (Statistics New Zealand, 2008) and the New Zealand Income Survey (Statistics New Zealand, 2009b). Data from all three surveys will help to understand the socio-economic background of this study's population.

In April 2008, the annual New Zealand Superannuation (aged pension) and war pension gross rates were NZ \$18,084 for a single person who lives alone and NZ \$27,494 for a couple (Work and Income, 2008) compared to the average annual household income from salaries and wages (gross) of NZ \$53,743.00 p.a. (Statistics New Zealand, 2008). Of those who are not in the labour force 21.7% said that they have a fair/poor health compared to 14.1% of those who are unemployed and 8.7% who are employed (Statistics New Zealand, 2009a). Those with an annual household income of NZ \$30,000 or less included retired people, beneficiaries and young people who did not work or only worked part-time while studying. (Statistics New Zealand, 2009a). **Figure 2:** One-quarter of people (24.6%) with an annual household income of \$30,000 or less reported having fair or poor health, and this proportion was three times higher than for people with an annual household income of \$100,001 or more (7.5%). Across all income groups 13.1% felt they had poor or fair health in Canterbury as compared to 15.0% in the other regions of the South Island and 10.9% in Auckland (Statistics New Zealand, 2009a). **Figure 2:** More than one in four people (26.0%) with an annual household income of \$30,000 or less reported having not enough money to meet everyday needs, more than any other income group. Across all income groups in Canterbury,

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13.4% felt they had not enough money to meet everyday needs as compared to 10.7% in Wellington and 17.5% in Auckland (Statistics New Zealand, 2009a).

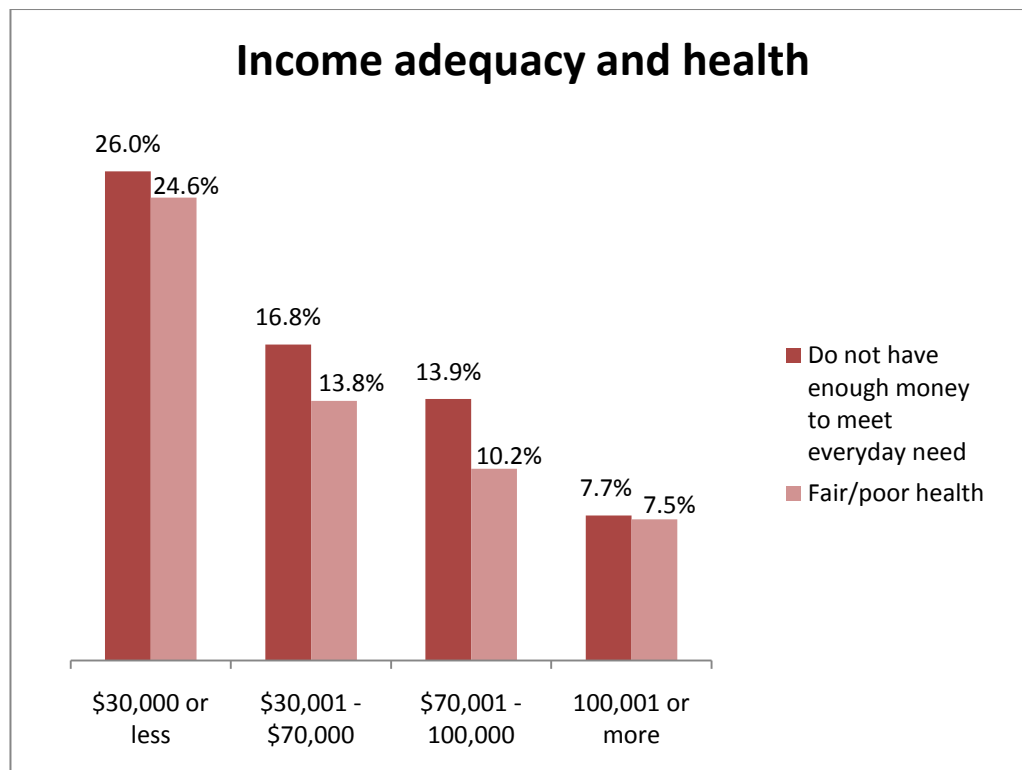


Figure 2: Income adequacy and health by income group (percentage)

Note. All income data are shown in NZ \$. Data adopted from the New Zealand Income Survey 2008 (Statistics New Zealand, 2009b).

The authors of a recently published survey conducted in New Zealand (Waldegrave & Cameron, 2009) pointed out that

(...) New Zealand has a unique profile, in that the universal NZS (New Zealand Superannuation) is paid above the 50 percent of median poverty line that OECD sets but below the 60 percent line that the European Union sets. As a result there are very few in deep poverty, but many older people who live around the higher poverty thresholds, either just above or below them. (p. 85)

Waldegrave and Cameron (2009) found that for respondents who were 65 years of age and older, the median personal income was NZ \$22,000 p.a. (gross), with an annual mean of NZ \$43,685. Almost three quarters (73%) of these respondents received between NZ \$10,000 and NZ \$30,000 p.a., with nearly half (48%) of all respondents who had incomes of NZ \$20,000 p.a. or less

(p. 89). From these findings the researchers concluded that many elderly people have little income other than the New Zealand Superannuation (p. 89).

Since the age groups that are at the highest risk for developing a dementia have in comparison with other age groups the lowest median weekly income (**Figure 3**) it is not surprising that many people living with dementia are reliant on welfare benefits as their main source of income.

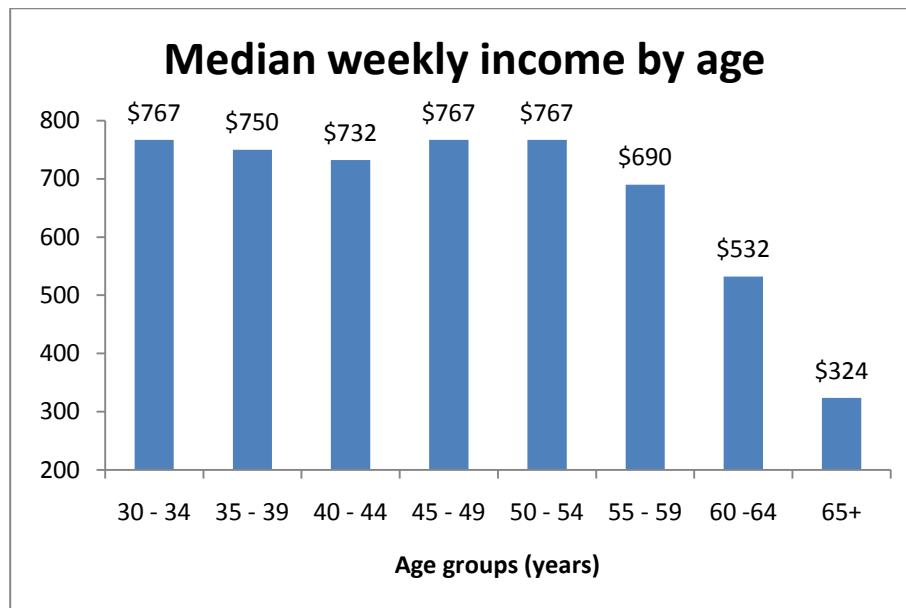


Figure 3: Median New Zealand weekly income according to age group

Note. All income data are shown in NZ \$. Data adopted from the New Zealand Income Survey 2008 (Statistics New Zealand, 2009b).

There are two main in-cash benefits that people with dementia can receive – the Invalids Benefit for those under 65 years of age and the aged pension (known as New Zealand Superannuation) for those 65 years of age and over. The Invalids Benefit provides (means tested) weekly payments for those who are unable to regularly work 15 hours or more a week because of a sickness, injury or disability which is expected to last at least 2 years. The following is an overview of financial support options available for PWDs and their caregivers (as of 2008):

1. Community Services Card

- a. younger than 65 years of age: depends on annual gross income: NZ \$23,712.00 single; NZ \$35,420.00 couple
- b. older than 65 years of age: incorporated into SuperGold Card/Veteran SuperGold Card

- c. "SuperGold Card" automatically eligible if on New Zealand Superannuation or if 65 of age or older and having some other benefit
- d. All services which are provided after needs assessment from The Princess Margaret Hospital are funded through government regardless of having a community services card or not.
- e. Only exception: domestic assistance is not funded if patient does not have community services card.
- f. This can only be publicly funded if the patient has a disability allowance.

2. Disability Allowance

- a. to help with ongoing, regular costs caused by a disability, such as doctor visits
- b. maximum NZ \$54.05 per week
- c. income tested (savings, assets, private pension): NZ \$27,363.96 singles, NZ \$39,813.80 married couple
- d. If maximum is reached, such as through other illness but dementia, some additional costs can be included in spouse's disability allowance (as long as it is for the direct benefit of the spouse, i.e. not dementia drugs, but cleaner).

3. Temporary additional support

- a. No limit but only to cover immediate costs, such as high rent, medical bills
- b. reviewed after 13 weeks to be re-approved
- c. asset tested
- d. NZ \$921.08 for a single/ NZ \$1,537.46 for a couple

4. Stop/ reduce work before aged 65: PWD

- a. If younger than 65 years of age and dementia is caused by head injury and the PWD can't work anymore ACC will pay (more than any other option). However, in most cases dementia is not caused by a head injury.
- b. If the PWD is younger than 65 years of age and the dementia not caused by a head injury and the PWD can't work anymore often he/she is first put on a sickness benefit (short term, expected for illness to improve and be able to work again) until the diagnosis is made. When a diagnosis of dementia is made, the PWD is switched to an invalid benefit (long term, patient not expected to be cured) until the age of 65 and then switched to New Zealand superannuation.

5. Stop/ reduce work before aged 65: Caregiver

- a. sickness/ invalid benefit: If the caregiver stops work to care for the patient they can both apply for benefit: invalid benefit = NZ \$383.66/week/couple (net in April 2008) for a couple with no children → automatically eligible for community services card, disability allowance and temporary support
- b. income tested such as continuous income from investments/ rental property etc. (house cannot be taken)
- c. domestic purposes benefit (caregiver benefit): only if the caregiver is somebody other than the spouse
- d. Payment for informal caregivers is not available yet but is being lobbied for by caregivers.

It follows a discussion on how to define QoL in dementia, on the advantages and disadvantages of self rated vs. proxy rated quality of life (1.2.2, p. 22), on the link between PWDs and their informal caregivers (1.2.3, p. 22), as well as on generic vs. illness-specific QoL scales (1.2.4, p. 23). The discussion is concluded by economic considerations (1.2.5, p. 24) and a summary (p. 26).

1.2 Quality of life in dementia

Currently it is not possible to cure dementia. So the main focus of dementia care is to promote well-being and maintain an optimal quality of life (Ettema, Droes, de Lange, Mellenbergh, & Ribbe, 2005a). Given the prevalence and burden of dementia and its impact on the allocation of resources for treatment and care, there is strong justification for assessing quality of life (QoL) in these persons and their caregivers in order to monitor changes to maintain or enhance the person with dementia's (PWD's) and the caregiver's QoL. Logsdon, Gibbons, McCurry and Teri (2002) concluded:

Reasons for measuring QOL in people with cognitive impairment are compelling. QOL assessments provide a format for individuals and their caregivers to express whether an intervention made an important difference in the patient's life. Such assessments allow researchers to draw conclusions about the extent to which treatments provide intended and "clinically significant" benefits. Furthermore, monitoring changes in QOL in individuals

with progressive cognitive impairment may suggest new areas of intervention to maintain or enhance life quality. (p. 511)

Assessment of QoL in general and in dementia in particular, however, is challenging for different reasons which will be discussed in the following sections.

1.2.1 Definition

The concept of QoL lacks a generally accepted definition. Despite this, as progress in the field has been made some agreement has emerged. For example, it is generally accepted that QoL is a multidimensional concept. This relates to the 1947 definition of "health" by the World Health Organization (WHO) as being "a state of complete physical, mental and social well-being" (World Health Organization, 1947). Similarly, Lawton (1994) characterised four QoL domains for persons with dementia (PWDs): cognitive functioning; ability to perform activities of daily living and to engage in meaningful time use; the ability to perform socially appropriate behaviour; and a favourable balance between positive and negative emotions. These four domains are a representation of Lawton's (1991) more generic definition of QoL as "the multidimensional evaluation, by both intrapersonal and social-normative criteria, of the person-environment system of the individual" (p. 6). Based on this definition, the author argued that four objective and subjective sectors are necessary to assess QoL in an elderly as well as a general population: behavioural competence, objective environment, perceived QoL and psychological well-being (Lawton, 1994, 1997). Lawton (1991) further explained that "each of the four sectors may in turn be differentiated into as many dimensions" (p. 8) as necessary for the individual purpose.

Some authors have tried to narrow the concept of QoL by considering only those aspects that can be affected by health care interventions. This concept is referred to as 'health-related quality of life' or HRQoL (Sloane, et al., 2005). Again, there is no uniform definition of this term which leads to competing views. In contrast to the concept suggested by Sloane, et al. (2005), the LASER-AD

study (Hoe, Katona, Roch, & Livingston, 2005) for example, refers to HRQoL instruments as important scales with which to measure a PWD's perception of global QoL.

1.2.2 Self-ratings vs. proxy-ratings

Even though most authors agree on the subjective nature of QoL, they draw different conclusions. Some conclude that only reports from PWDs will lead to valid data (Brod, Stewart, Sands, & Walton, 1999). Others consider that proxy-reports will also provide valid data (Rabins, 2000). Since dementia affects patients' cognitive abilities such as communication and insight, doubts have been raised about the reliability and validity of those patients' QoL self-ratings (Ettema, et al., 2005a). However, bearing in mind that caregivers' proxy-ratings of PWDs' QoL are influenced by their own QoL (Fuh & Wang, 2006; Ready, Ott, & Grace, 2004; Vogel, Mortensen, Hasselbalch, Andersen, & Waldemar, 2006), it has been argued that "proxy-ratings can be considered as a complementary information for self-ratings but not as a substitute" (Riepe, et al., 2009). Depending on PWDs' level of cognitive impairment, it can be argued that PWDs' QoL is best assessed by obtaining both PWDs' self-ratings as well as caregivers' proxy-ratings. It can be further argued that, from an ethical point of view, PWDs' perspectives should always be considered, regardless of their impairments.

1.2.3 Interrelation between person with dementia and caregiver

It has been shown that PWDs' QoL and caregivers' QoL are inter-connected and that both share some level of distress (Thomas, et al., 2006). Schulz and Martire (2004) criticised in their dementia-caregiving review that, despite the fact that caregiving by definition occurs in a relational context, very little research had focussed on the impact that patients and caregivers have on each other. The authors concluded from some non-dementia specific research that the similarities in affect in patients and caregivers would be an indicator for such joint impact which could also negatively influence each other's QoL. Schulz and Martire (2004) further concluded that interventions might be most successful if they would focus on both patients and caregivers. It has been emphasised for more than a decade how important it is for studies to treat PWDs and their

caregivers as a unit and consequently to measure the QoL of both parties (Salek, Walker, & Bayer, 1998; Scholzel-Dorenbos, et al., 2007).

1.2.4 Generic vs. dementia-specific scales

Another significant reason for the difficulties of assessing QoL in dementia is that generic QoL instruments have widely been used in dementia research (Kurz, Scuvee-Moreau, Vernooij-Dassen, & Dresse, 2003; Lopez-Bastida, Serrano-Aguilar, Perestelo-Perez, & Oliva-Moreno, 2006). Generic assessment tools often focus on health aspects of QoL, raising the question of their validity in dementia studies compared to disease-specific instruments (Ettema, et al., 2005a). It has been concluded that disease-specific instruments are to be preferred, certainly when the study focuses primarily on people with dementia (Ettema, et al., 2005a).

The same could be true for assessment tools of caregivers' QoL. Bell, Araki and Neumann (2001) used two generic assessment tools, the SF-36 and the HUI:2, in a large population of 679 caregivers of people with AD. The authors found no significant differences between HRQoL outcomes for caregivers in different settings as well as across different stages of the illness. They concluded that generic preference-weighted instruments may not adequately reflect HRQoL in such a population, thus requiring the development of a condition-specific instrument. This conclusion is supported by studies which have demonstrated the differences between a caregiver population and any other population investigated. It was shown that caregivers have poorer physical and psychological health outcomes than non-caregivers (Brodsky, et al., 2003). Furthermore, it has been shown that dementia-caregivers, in comparison with caregivers of physically impaired older adults, reported more stress-related outcomes having a worse impact (Schulz & Martire, 2004). The distinct features of dementia, such as neuropsychiatric and behavioural symptoms, trigger distinct reactions, symptoms and coping mechanisms in caregivers of PWDs including depression (Covinsky, et al., 2003) and increased risk of physical health problems (Kurz, et al., 2003) which are a major reason for admission of PWDs into residential care (Cummings, et al., 1994). Bell, et al.'s (2001) findings, therefore, are not surprising and their call

for the development of an illness-specific assessment tool of caregiver HRQoL could be expanded into a scale which comprises all aspects of QoL, including HRQoL.

The first steps have been taken towards developing a QoL scale specifically for family-caregivers of PWDs. For the PIXEL study, the authors (Thomas, et al., 2002a; 2006) developed a scale measuring the QoL of 100 informal caregivers of PWDs which had been validated in France (Thomas, et al., 2004) showing the close relationship between PWDs' and caregivers' QoL. Vickrey, et al. (2009) only recently reviewed measures to assess dementia caregivers' QoL. They found that the PIXEL group was the only one that did not use generic QoL measures or narrower substitutes such as burden or depression to assess dementia-caregivers' QoL. Vickrey, et al. (2009), however, criticised the PIXEL study group because it had only measured the negative aspects of caregiving without considering positive aspects such as faith and spirituality. The authors therefore developed a comprehensive instrument for measuring the QoL (including HRQoL) of PWDs' caregivers from different ethnic backgrounds. Preliminary results showed excellent internal consistency reliability. Adequate test-retest reliability, however, was shown for only 6 of the 10 scales of which the tool comprises. The authors recommended further evaluation in a larger sample. In a QoL discussion paper, Riepe et al. (2009) acknowledged the importance of both generic and disease-specific assessment scales. The authors suggested that generic scales would provide important information regarding PWDs' general health status, enabling evaluation of the effectiveness of interventions, whereas disease-specific QoL scales could be expected to be more sensitive and responsive to changes in different patient groups.

1.2.5 Quality of life and economic aspects of dementia

Worldwide, the number of people with dementia is steadily increasing, causing a rapid growth of costs in dementia care (Access Economics, 2006, 2008; Wimo, Ljunggren, & Winblad, 1997). It seems crucial therefore that dementia QoL studies should also consider an economic perspective. The opposite approach – economic evaluations taking QoL into account – has already been

requested: more than 10 years ago Wimo and colleagues (Wimo, et al., 1997) made the following suggestion:

In a complete health economic evaluation, both costs and outcome should be included when care alternatives are compared. Such studies are rare. It is logical to consider quality of life as the most relevant outcome measurement of dementia care. ... The need for studies in this field is obvious. (p. 852)

However, in 2004, closer to the commencement of this current study, it was still noted by van den Berg, Brouwer, and Koopmanschap (2004) that, for example, “informal care is often neglected in economic evaluations of health care programs” (p. 44). The authors pointed out further:

The incorporation of informal care in economic evaluations is, however, crucial to prevent undesirable policy recommendations. Informal care should not be treated as “free” in economic evaluations, as this may lead to cost-ineffective care strategies from a societal perspective and even to health damage in the population at large. (p. 44)

Van den Berg, et al. (2004) also suggested that

[...] informal care could also be valued by registering changes in well-being of informal caregivers. An advantage of this method is that it allows economic and non-economic factors affecting the preferences of an individual to be combined. To our knowledge, no research has been done using this concept to value informal care. (p. 43)

Van den Berg, et al. (2004) outlined a number of methodological issues of incorporating informal care into economic evaluations. They recommended the use of the opportunity cost method or wage-replacement method complemented by other measures such as (health-related) QoL until the development of a more appropriate approach (p. 44).

1.2.6 Summary

Despite these difficulties and a need for further methodological research (Gauthier, 1998), QoL is becoming an important dimension of Alzheimer's disease therapeutic research (Dixon, Walker, & Salek, 2006). It has been predicted that it may become the major outcome measure in dementia research (Ettema, et al., 2005a). In 2008 a European consensus emerged, recommending the use of patient and caregiver QoL as outcome measures for psychosocial intervention research in dementia care (Moniz-Cook, et al., 2008a).

2 Systematic literature review

2.1 Introduction

The number of studies dealing with QoL in dementia has grown significantly in the past 10 years and a number of reviews have been published in this field. To date, most of these reviews have focused on QoL instruments and their psychometric data (Ettema, et al., 2005a; Salek, et al., 1998; Scholzel-Dorenbos, et al., 2007; Walker, Salek, & Bayer, 1998). In dementia research in general, there have been a number of reviews regarding pharmacological (Birks & Flicker, 2000; Birks & Grimley Evans, 2007; Hudson & Tabet, 2003; Li, Wu, Zhou, Liu, & Dong, 2008; Rands, Orrell, & Spector Aimee, 2000) and non-pharmacological interventions (Lee & Cameron, 2004; C. Thompson, et al., 2007; Thorgrimsen, Spector, Wiles, & Orrell, 2003). It should be mentioned, nevertheless, that very few reviews, either pharmacological (Clegg, et al., 2002) or non-pharmacological (Schulz, et al., 2002; Woods, Spector, Jones, Orrell, & Davies, 2005), have included QoL as an explicit outcome.

One of the most recent reviews published in the field of dementia research was conducted by Banerjee, et al. (2009), who summarised the predictive and explanatory value of HRQoL. By including socio-demographic characteristics as outcome measures, such as age and care setting, they followed a rather broad concept of HRQoL. Even though the result was a comprehensive review regarding QoL, it still had some limitations: papers on caregivers' QoL were excluded from the review (if they did not relate to measures of patient QoL) as well as papers dealing with economic aspects or pharmaceutical interventions. One aim of this study is to address these limitations.

Unlike previous publications, the review undertaken for this research does not focus on QoL instruments and their psychometric data. Complementing Banerjee, et al.'s (2009) recent evaluation, the analysis which follows herein systematically reviews variables predicting QoL in dementia of both the PWD as well as his/her family-caregiver. Studies on formal and informal

supports, including pharmaceutical interventions, are considered as long as QoL was an explicit outcome measured using a disease-specific instrument. The inclusion of such intervention studies is particularly important since most reviews in dementia research to date still lack QoL as an outcome measure. Several systematic Cochrane Reviews conducted between 2000 and 2008 included QoL as a variable into their search strategies but often the reviews did not identify data on this outcome measure (Birks & Flicker, 2000; Birks & Grimley Evans, 2007; Li, et al., 2008; Rands, et al., 2000; Rodriguez-Martin, Qizilbash, & Lopez-Arrieta, 2001). In cases where the Cochrane Reviews could identify a study that reported QoL as an outcome, a disease-specific scale to assess QoL in dementia was not used (Birks & Harvey, 2006).

As outlined previously, there is an urgent need for QoL studies which include an economic perspective in the analysis. To date, no literature review has been identified that evaluates the current status of QoL research relative to economic aspects.

This review, even though it followed a systematic approach, is different from other “classic” systematic evaluations, such as analyses of the effectiveness of pharmacological interventions. Studies were not appraised based on common quality criteria, such as the inclusion of control groups or the level of randomisation. Instead, the methodology of how QoL was assessed, as well as the outcomes chosen to predict QoL in dementia were important factors which determined if a study was to be included or excluded.

The aim of this review was to answer the following questions:

1. Which clinical and non-clinical variables are associated with QoL of PWDs?
2. Which clinical and non-clinical variables are associated with QoL of family-caregivers when they care for a PWD?
3. What kinds of formal support or intervention have an impact on PWDs’ or their family-caregivers’ QoL?
4. What kinds of informal support or intervention have an impact on PWDs’ or their family-caregivers’ QoL?
5. What is known about QoL in dementia from an economic viewpoint?

In consequence, this review has three important functions: firstly, to obtain a comprehensive understanding of clinical and non-clinical predictors of QoL in dementia; secondly, to evaluate the current knowledge of QoL in dementia from a clinical, therapeutic and economic perspective, and thirdly to identify potential gaps of knowledge which require further investigation.

2.2 Methodology

Considering the general consensus that QoL is a multidimensional concept, the following systematic review is based on a broad concept of QoL including HRQoL. A dementia-specific QoL definition, offered in 2005, summarised such a broad concept: “dementia specific QOL is the multidimensional evaluation of the person-environment system of the individual, in terms of adaptation to the perceived consequences of the dementia” (Ettema, et al., 2005b). Worldwide, one of the most accepted and widely used instruments to measure QoL in dementia is the “Quality of Life - Alzheimer’s Disease scale” (QOL-AD) (Logsdon, et al., 2002). The authors selected QoL measures to reflect each of Lawton’s (1994) four conceptual QoL domains in older adults: behavioural competence, objective environment, perceived QoL and psychological well-being. Logsdon, et al. (Logsdon, Gibbons, McCurry, & Teri, 1999) summarised the development of the QOL-AD as including “the patient’s and caregiver’s appraisal of the patient’s physical condition, mood, interpersonal relationships, ability to participate in meaningful activities, financial situation, and an overall assessment of self as a whole and life quality as a whole” (p. 24).

The keywords applied to this review were selected to reflect Lawton’s original concept of QoL in AD and Logsdon’s development of the QOL-AD. Furthermore, because this study not only assessed patients’ QoL but equally focused on caregivers’ QoL, attention was paid to caregivers’ interpersonal relationships. The perceived level of social support from family and friends was hypothesised to be a predictor of caregivers’ and PWDs’ QoL. Keywords used in the database searches were chosen accordingly.

To complement clinical and interpersonal factors predicting QoL in dementia, two further aspects were chosen to be reviewed: firstly, formal and informal supports and interventions, secondly, economic aspects, that is, costs of interventions (including drugs) and financial burden for the caregiver.

Given the importance of a PWD-caregiver unit (Walker, et al., 1998) this review is based on a systemic approach. Not only were studies regarding PWDs' QoL considered, but also studies regarding family-caregivers' QoL.

This review was conducted in two steps:

- 1. Level-1 papers:** Only those studies using disease-specific instruments to measure QoL were included. Pharmacological and non-pharmacological intervention studies as well as economic analyses were only included if QoL was an explicit outcome measured using a disease-specific instrument. This criterion was also applied to papers that analysed caregivers' QoL.
- 2. Level-2 papers:** It was also important to consider studies which did not fulfil all criteria for a level-1 paper because for some aspects, such as economics, very few or no level-1 papers were identified. Furthermore, this second appraisal also included those Cochrane Reviews² whose authors explicitly searched for QoL articles but did not identify any. Some references were included even though they did not focus on QoL as an explicit outcome. These were studies which provided important additional information on one of the QoL predictors identified in step one, such as depression.

The terminology of 'level-1' and 'level-2 papers' was chosen to express a hierarchy of quality of publications. However, the quality criteria were not defined by using the traditional approach of appraisal of publications for systematic reviews, whereby a study would have to be a randomised

² <http://www.cochrane.org/reviews/>

controlled trial in order to be graded as a level-1 paper. Instead, the criteria were set based on the outcomes at which this review aimed.

Three databases were explored: PubMed, the Cochrane Reviews database and the Centre for Reviews and Dissemination (CDR) database. Articles were also cross referenced and manually searched, resulting in an additional 55 papers. Databases were investigated using the following keywords³ (Table 2) limited to title/abstract where possible:

Table 2: Keywords utilised to search databases

PWD	Caregiver/carer	Support/ Interventions	Economic aspects
1. Quality of life	6. Quality of life	11. Formal support/ intervention	
2. Depression	7. Burden		
3. Cognition	8. Depression		13. Cost/ income
4. Behaviour/behavior	9. Perceived social support	12. Informal support/ intervention	
5. Functioning	10. Financial/ economic burden		

The systematic search strategy was conducted as follows:

A) Search for articles concerned with the QoL in dementia using keywords 1 and 6:

a. QoL + dementia

- i. This was the only examination of the CDR database because only 17 references were identified. Further limitation by using more specific keywords, such as 'Alzheimer*' would not have been useful.
- ii. The same keywords applied to PubMed and Cochrane resulted in too many references (n = 969) including irrelevant papers. Both databases were examined again using the following criteria:

³ Keywords reflect Lawton's domains without using the exact same wording, for example: physical functioning as compared to daily functioning/ADL.

- b. QoL + dementia (limited to title)
- c. QoL + Alzheimer* (limited to title)
- d. QoL + measure⁴

Examinations b, c and d resulted in fewer (n = 189) and more relevant hits.

B) Detection of PWDs'/caregivers' QoL predictors using keywords 2-10:

- a. PWD: QoL + dementia + keywords 2/3/4/5
- b. Caregiver: QoL + dementia + keywords 6/7/8/9/10

C) Identification of interventions that improve or at least sustain QoL:

- a. QoL + dementia + formal support/ formal intervention using keyword 11
- b. QoL + dementia + informal support/ informal intervention using keyword 12

D) Keywords for cost benefit analysis of interventions:

- a. QoL + dementia + formal cost*/income using keyword 13

⁴ This was necessary so as to make sure that QoL was measured explicitly as a dependent variable/ outcome and not just as an indirectly implied outcome.

The following table gives a detailed overview of all the systematic literature searches conducted and the number of references identified (Table 3):

Table 3: Databases searched and number of articles identified

Database searched:		A: PubMed	B: Cochrane	C: CRD ⁵	After merging results from A, B and C, and after removing duplicates using EndNote ⁷
Limitations:		Limits: Title, abstract; 01.01.1980 – 15.11.2008; German, English; Human	Limits: Title, abstract, keywords; 1980-2008	Limits: 1980 – 1999 ⁶	
Search	Keywords				
1a.	quality of life AND dementia	(864)	(158) ⁸	17	17
1b.	quality of life dementia/ Alzheimer* (limited to title)	115 (dementia) + 55 (Alzheimer*) = 170	23 (dementia), 12 (Alzheimer*) = 35		189
2.	quality of life AND measure AND dementia	93	82		158
3.	quality of life dementia depression	168	28		180
4.	quality of life dementia cognition	87	51		120
5.	quality of life dementia behaviour/behavior	45 (behaviour) + 52 (behavior) = 93	36		121
6.	quality of life dementia functioning	69	43		107
7.	quality of life dementia burden	78	18		88
8.	quality of life dementia carer/ caregiver depression	2 (carer) + 29 (caregiver) = 31	1 (carer) + 6 (caregiver) = 7		34

⁵ Centre for Reviews and Dissemination database.

⁶ From 2000 onwards CRD references are included in Cochrane database.

⁷ EndNote bibliographical management system: www.endnote.com

⁸ (864 + 158) - 53 duplicates = 969 articles which were not included in the further calculations

Table 3: Databases searched and number of articles identified (*continued*)

Database searched:	A: PubMed	B: Cochrane	C: CRD ⁹	After merging results from A, B and C, and after removing duplicates using EndNote ¹¹
Limitations:	Limits: Title, abstract; 01.01.1980 – 15.11.2008; German, English; Human	Limits: Title, abstract, keywords; 1980-2008	Limits: 1980 – 1999 ¹⁰	
Search	Keywords			
9.	quality of life dementia carer/ caregiver perceived social support	8	1 (carer) + 13 (caregiver: <i>full text search</i> , <i>otherwise 0</i>) = 14	21
10.	quality of life dementia financial/economic burden	10 (financial burden) + 11 (economic burden) = 21	Financial burden OR economic burden: 179	194
11.	quality of life dementia formal support/intervention	5 (formal support) + 5 (formal intervention) = 10	Formal support OR formal intervention: 270	274
12.	quality of life dementia informal support/intervention	9 (informal support) + 8 (informal intervention) = 17	Informal support OR informal intervention: 116	125
13.	quality of life dementia cost*/income	74 (cost*) + 1 (income) = 75	44 (cost*) + 0 (income) = 44	110
14.	quality of life dementia support	101	43	132
Sum of searches 1a. - 14. after merging results from databases A, B and C, and after removing duplicates using EndNote:				1870
Number of duplicates identified manually:				800
Sum after removing 800 duplicates:				1070
Number of articles identified manually via cross-referencing:				52
SUM of all articles minus duplicates:				= 1122

⁹ Centre for Reviews and Dissemination database¹⁰ From 2000 onwards CRD references are included in Cochrane database.¹¹ EndNote bibliographical management system: www.endnote.com

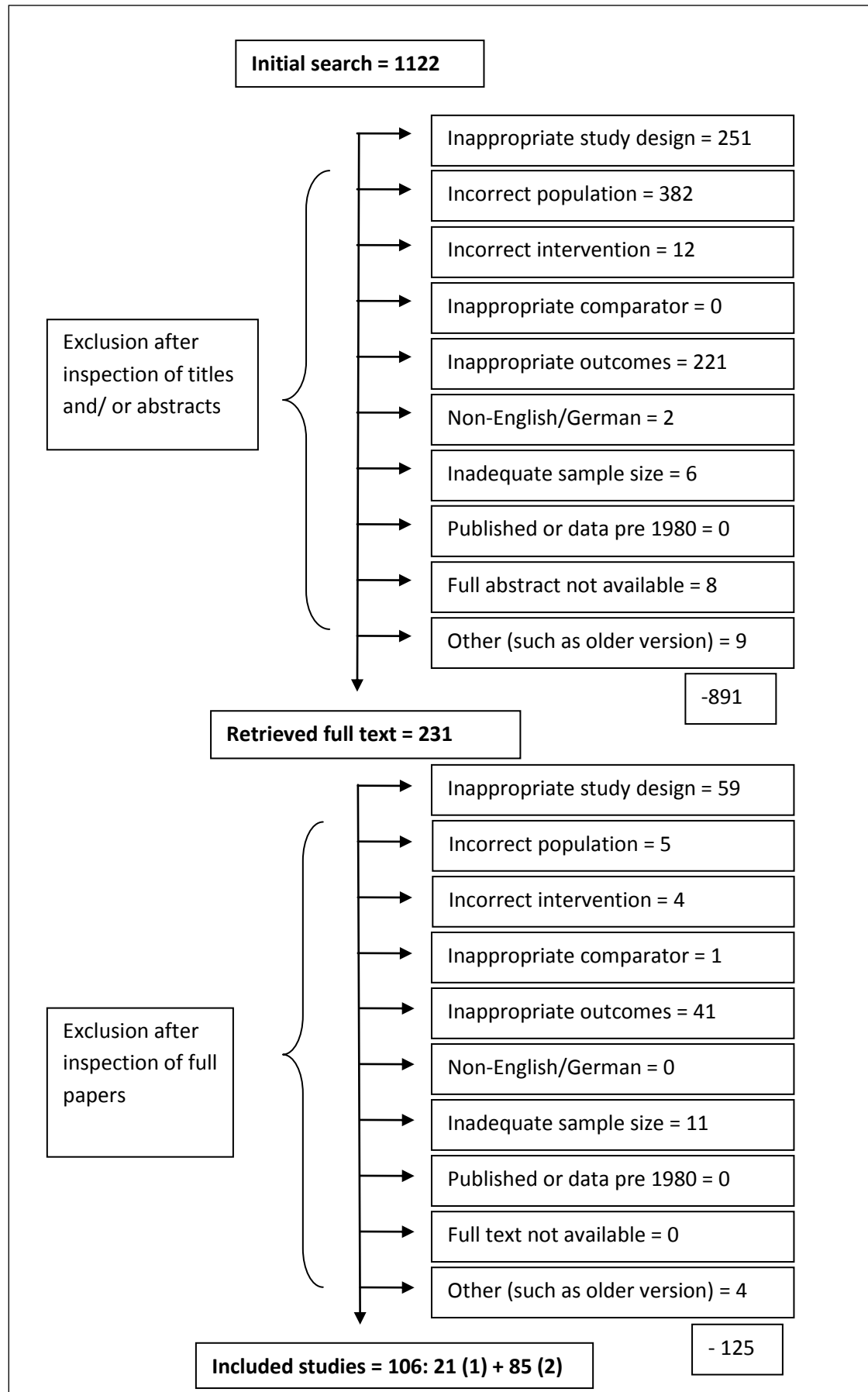
After removing all duplicates, 1122 articles remained for review. References were not included for review if they fulfilled one or more of the exclusion criteria specified in Table 4.

Table 4: Criteria applied to exclude articles

E1 STUDY DESIGN	–	Non-systematic (narrative) review, case reports, notes letters, editorials, abstracts.
	–	Wrong settings (nursing homes, assisted living etc.).
	–	QoL as measured by SF36, SF12 etc., i.e. non-dementia specific.
	–	QoL measured with a single item (since QoL is a multidimensional construct).
E2 INCORRECT POPULATION	–	Sample or subset of sample not diagnosed with dementia or not caregivers of PWD.
	–	Not stroke: only if also diagnosed with cognitive impairment (=VD or mixed dementia).
	–	Not Hutchinson, Huntington, Parkinson, depression (if not comorbidity of dementia or outcome for C)
E3 INCORRECT INTERVENTION	–	Not formal or informal services, medication, treatment, intervention to slow down dementia or to improve dementia symptoms or to sustain QoL of PWD or C (only with QoL as explicit outcome).
	–	Not comparable with New Zealand health system.
E4 INAPPROPRIATE COMPARATOR	–	Not if comparator is not fulfilling criteria which apply to population/sample, e.g. relevant outcomes.
E5 INAPPROPRIATE OUTCOMES	–	Non assessment of dementia symptoms with QoL for PWD and C. as dependent variable and QoL factors (ADL, depression, behaviours, interpersonal environment, functioning, economic burden).
	–	Non evaluation of interventions for PWD and C. with QoL and QoL factors as outcomes of those interventions.
	–	Non cost-benefit analyses of those interventions.
	–	Assessment/development of QoL scales (only included in review if paper reports instrument's relation to clinical QoL variables).
E6 NON-ENGLISH, NON- GERMAN		
E7 INADEQUATE SAMPLE SIZE	–	< 20 participants of sample or of subset or of intervention group of sample diagnosed with dementia.
E8 INCORRECT PUBLICATION DATE RANGE	–	01.01.1980 – 15.11.2008 (PubMed).
	–	1980 – 2008 (Cochrane).
	–	1980 – 1999 (CDR): from 2000 included in Cochrane.
E9 FULL TEXT OR ABSTRACT NOT AVAILABLE	–	Article withdrawn.
E10 OTHER	–	Text surpassed (older version of text, esp. Cochrane).
	–	Same study/ results only published in different journals.
	–	Dementia drug not used anymore.

All 1122 references identified were first reviewed based on their title and abstract and 891 references were excluded consistent with the outlined exclusion criteria. The remaining 231 references were retrieved as full text papers and after reading all of them a further 125 papers were excluded. The remaining 106 papers were included into the systematic review. Only 21 papers fulfilled the criterion of using illness-specific instruments to measure QoL in dementia and were included as level-1 papers. The remaining 85 papers were included as level-2 papers. The review process is presented in the following graph (Figure 4):

Figure 4: Retrieval process of included studies



2.3 Results

The following sections summarise the findings of the systematically reviewed papers regarding clinical patient (2.3.1, p. 39) and caregiver outcomes (2.3.2, p. 61) and non-clinical QoL measures, including formal interventions and supports (2.3.3, p. 66) and the economic impact of dementia on QoL (2.3.4, p. 95).

More than 1000 articles ($n = 1122$) were reviewed for inclusion, of which 21 were graded as level-1 publications. An additional 85 publications were graded level-2. Of these 85 papers 19 were ranked as key-articles for the two domains for which no level-1 paper could be identified ('Informal interventions' and 'Economics'). The review was therefore based on 106 publications, including 40 key-articles. Table 5 (p. 38) summarises the number of key-articles identified for each domain: 21 level-1 papers for the domains 'Clinical QoL measures' and 'Formal interventions', as well as 19 level-2 papers for the domains 'Informal interventions' and 'Economics'.

Table 5: Number of included key-articles for each quality of life domain and sub-domain

Domain	Sub-domain	Level-1 papers (Appendix A) n	Level-2 papers ¹² (Appendix B) n
Clinical QoL measures: Table 6, p. 40	Patient	10	
	Patient/Caregiver	2	
	Concept and measures of QoL	2	
Formal interventions	Pharmacological	1	
	Non-pharmacological	6	
Economics	Direct medical costs	-	10
	Direct non-medical costs (informal caregiving hours)	-	8
	Indirect costs	-	(2 ¹³)
	Financial burden	-	1 (3 ¹⁴)
Total		21	19

¹² Only those level-2 papers which were reviewed in detail if no level-1 paper was identified for that domain

¹³ These are no additional articles but ones that have already been identified for 'direct medical costs'.

¹⁴ These are no additional articles but ones that have already been identified for 'direct non-medical costs'.

2.3.1 Clinical measures of patient quality of life

The clinical and non-clinical variables were chosen to predict QoL in dementia in patients and their caregivers based on Lawton's original concept of QoL in AD (Lawton, 1994) and Logsdon's development of the QOL-AD (Logsdon, et al., 2002). Please refer to chapter 2.2 (p. 29) for further details. In representation of Lawton's "interpersonal environment" domain (Lawton, 1994), the databases were searched using the keywords *perceived social support* as well as *informal support/intervention*.

2.3.1.1 Patient quality of life per se

Twelve original studies graded level-1 that evaluated the QoL of PWDs were identified including two studies that also measured the caregivers' QoL. In addition, two systematic reviews of literature were also graded level-1 publications. Both reviews investigated the concept and measures of QoL in dementia. All 12 original studies are discussed in the following sections depending on which outcomes researchers assessed in addition to QoL.

The characteristics and results of 12 original studies and two systematic reviews are presented in Table 6 (p. 40).

Table 6: Study characteristics and results of level-1 papers

Publication	Participants/Study design	Clinical outcome measures ¹⁵	Rating scales	Statistically significant correlations/associations
		Patient QoL ¹⁶ ($n = 10$)		
Banerjee, et al. (2006)	Mild - moderate dementia (MMSE >9) PWD ¹⁷ : $n = 101$ Caregiver: $n = 99$ Cross sectional study UK	QoL proxy rated ¹⁸ Cognition Behaviours Functioning Caregiver mental health	DEMQOL MMSE NPI Barthel Index (ADL) GHQ-12	→ DEMQOL and total NPI ($r = -.41, p < .001$) → DEMQOL and NPI agitation ($r = -.34, p = .001$) → DEMQOL and NPI depression ($r = -.47, p < .001$) → DEMQOL and NPI anxiety ($r = -.30, p = .005$) → DEMQOL and NPI disinhibition ($r = -.23, p = .038$) → DEMQOL and NPI irritability ($r = -.35, p = .001$) → DEMQOL and age PWD ($r = .33, p = .007$): increasing age → better QoL → GHQ-12 and DEMQOL ratings ($r = -.21, p = .046$)
Edelman, Fulton, & Kuhn (2004)	Different stages of dementia PWD: $n = 54$ Subsample: PWD: $n = 36$ (mild - moderate dementia, MMSE > 9) Staff Cross sectional study USA	QoL patient rated QoL proxy rated Cognition Depression Functioning Comorbid medical conditions	DQoL, Client Quality of Life-AD Staff Quality of Life-AD, ADRQOL, DCM MMSE CSDD Katz's ADL The Cumulative Illness Rating Scale-Geriatrics (Miller, et al., 1992)	$n = 54$ → Staff Quality of Life-AD and MMSE ($r = .41, p = .002$) → Staff Quality of Life-AD and ADL ($r = -.63, p < .001$) → ADRQOL and MMSE ($r = .50, p < .001$) → ADRQOL and ADL ($r = -.62, p < .001$) → DCM and ADL ($r = -.46, p < .001$) → Staff QoL ratings correlated strongly (positively) with each other. $n = 36$ DQoL and Client Quality of Life-AD ($r = .56, p < .001$)

¹⁵ All outcomes are patient related unless stated otherwise.¹⁶ Quality of life¹⁷ Person with dementia¹⁸ Unless stated otherwise outcome measures are patient related

Table 6: Study characteristics and results of level-1 papers (*continued*)

Publication	Participants/Study design	Clinical outcome measures	Rating scales	Statistically significant correlations/associations
		<i>Patient QoL (n = 10)</i>		
Fuh & Wang (2006)	Mild – moderate AD ¹⁹ (MMSE > 9) PWD: n = 90 Caregiver: n = 81 Cross sectional study Taiwan	QoL patient rated QoL proxy rated Severity of dementia Cognition Behaviours Functioning Caregiver distress	QOL-AD QOL-AD CDR (correlations not reported) MMSE NPI Blessed ADL NPI-D	→ Trend of correlation: QOL-AD proxy and NPI-D ($r = -.203, p = .08$) → Discrepancy score (QOL-AD proxy minus QOL-AD patient) and NPI-D ($r = .253, p = .03$)

¹⁹ Alzheimer's disease

Table 6: Study characteristics and results of level-1 papers (*continued*)

Publication	Participants/Study design	Clinical outcome measures	Rating scales	Statistically significant correlations/associations
		<i>Patient QoL (n = 10)</i>		
Hurt, et al. (2008)	<p>Mild – moderate AD, VD²⁰, mixed dementia</p> <p>PWD: <i>n</i> = 46 Caregiver: <i>n</i> = 116</p> <p>Cross sectional multi-centre study</p> <p>7 European centres in France, UK and Greece</p>	<p>QoL patient rated QoL proxy rated Cognition Behaviours</p> <p>Apathy patient rated Apathy proxy rated</p> <p>Caregiver distress</p>	<p>QOL-AD QOL-AD MMSE NPI, The BPSD questionnaire (Hurt, et al., 2008)</p> <p>The Apathy Inventory²¹ (Robert, et al., 2002)</p> <p>NPI-D, BPSD distress</p>	<p><i>n</i> = 46 → QOL-AD patient and NPI delusions ($\rho = -.340, p = .021$) → QOL-AD patient and Apathy Inventory (patient rated) lack of interest ($\rho = -.495, p = .000$)</p> <p><i>n</i> = 116 → QOL-AD proxy and MMSE ($\rho = .311, p < .01$) → QOL-AD proxy and NPI (negatively): delusions, hallucinations, agitation, depression, apathy, irritability, sleep disturbance, total score ($\rho = -.598, p < .001$) → QOL-AD proxy and BPSD (negatively): shouting/screaming, misidentification, hoarding, mirror sign, change in personality → QOL-AD proxy and Apathy Inventory (negatively) all carer ratings → QOL-AD proxy and Apathy Inventory (negatively) patient rated lack of initiative, Apathy Inventory total score → QOL-AD proxy and most (9/13) NPI-D items, including NPI-D total score ($\rho = -.547, p < .001$) → QOL-AD proxy and most (5/7) BPSD distress items → QOL-AD proxy predicted significantly by NPI depression, NPI irritability, Apathy Inventory (carer rated), NPI-D irritability</p>

²⁰ Vascular dementia²¹ The scale evaluates patient and caregiver perceptions of patient apathy (Robert, et al., 2002).

Table 6: Study characteristics and results of level-1 papers (continued)

Publication	Participants/Study design	Clinical outcome measures	Rating scales	Statistically significant correlations/associations
		Patient QoL ($n = 10$)		
Logsdon, et al. (2002)	<p>Different stages of AD</p> <p>PWD: $n = 155$ (completers of the QOL-AD)</p> <p>Mild AD (MMSE < 17): $n = 57$ Moderate AD (MMSE = 17-21): $n = 51$ Severe AD (MMSE > 21): $n = 47$ Caregiver: $n = 155$</p> <p>Cross sectional study</p> <p>USA</p>	<p>QoL patient rated</p> <p>QoL proxy rated</p> <p>Cognition</p> <p>Depression</p> <p>Behaviours</p> <p>Functioning</p> <p>Pleasant event frequency</p> <p>Physical health</p> <p>Caregiver burden</p> <p>Caregiver depression</p>	<p>QOL-AD</p> <p>QOL-AD</p> <p>MMSE</p> <p>GDS</p> <p>RMBPC</p> <p>The Physical and Instrumental Self-Maintenance Scale (ADL, IADL)</p> <p>The Pleasant Events Schedule-AD-Short Form (PES-AD) (Logsdon & Teri, 1997; Teri & Logsdon, 1991)</p> <p>2 subscales of the Medical Outcomes Study (MOS) 36-item short form (Stewart, Hays, & Ware, 1988)</p> <p>The Screen for Caregiver Burden (SCB) (Vitaliano, Russo, Young, Becker, & Maiuro, 1991)</p> <p>CESD</p>	<p>$n = 155$</p> <p>→ QOL-AD patient and ADL ($r = -.31, p < .001$)</p> <p>→ QOL-AD patient and RMBPC depression ($r = -0.22, p < .01$)</p> <p>→ QOL-AD patient and PES-AD ($r = .30, p < .001$)</p> <p>→ QOL-AD patient and GDS ($r = -.51, p < .001$)</p> <p>→ QOL-AD patient and MOS physical function ($r = .22, p < .01$)</p> <p>→ QOL-AD patient and SCB objective burden ($r = -.21, p < .01$)</p> <p>→ QOL-AD patient and SCB subjective burden ($r = -.19, p < .01$)</p> <p>→ QOL-AD proxy and ADL, IADL, RMBPC memory and disruption, GDS, SCB, CESD all highly negatively correlated ($p < .001$)</p> <p>→ QOL-AD proxy and RMBPC depression ($r = -.23, p < .01$)</p> <p>→ QOL-AD proxy and PES-AD, MOS positively correlated</p> <p>$n = 57$</p> <p>→ QOL-AD patient and ADL ($r = -.31, p < .05$)</p> <p>→ QOL-AD patient and PES-AD ($r = .32, p < .05$)</p> <p>→ QOL-AD patient and GDS ($r = -.51, p < .001$)</p> <p>→ QOL-AD proxy and ADL, GDS, SCB, CESD negatively correlated</p> <p>→ QOL-AD proxy and PES-AD, MOS physical function pos. correlated</p> <p>$n = 51$</p> <p>→ QOL-AD patient and ADL, RMBPC memory and disruption, GDS, SCB negatively correlated</p> <p>→ QOL-AD patient and MOS positively correlated</p> <p>→ QOL-AD proxy and all outcomes (but MOS role limits) correlated</p> <p>$n = 47$</p> <p>→ QOL-AD patient and PES-AD ($r = 0.41, p < .01$)</p> <p>→ QOL-AD patient and GDS ($r = -0.41, p < .01$)</p> <p>→ QOL-AD proxy and IADL, RMBPC memory and disruption, GDS, SCB, CESD negatively correlated</p> <p>→ QOL-AD proxy and PES-AD, MOS physical function positively correlated</p>

Table 6: Study characteristics and results of level-1 papers (*continued*)

Publication	Participants/Study design	Clinical outcome measures	Rating scales	Statistically significant correlations/associations
		<i>Patient QoL (n = 10)</i>		
Matsui, et al. (2006)	Mild – moderate AD (MMSE > 10) PWD: n = 140 Caregiver: n = 140 Cross sectional study Japan	QoL patient rated QoL proxy rated Cognition Behaviours Functioning	QOL-AD QOL-AD MMSE, Short Memory Questionnaire (Koss, Patterson, Ownby, Stuckey, & Whitehouse, 1993) NPI HADL	MMSE ≥ 21 → QOL-AD patient and MMSE ($\rho < .001, p < .001$) → QOL-AD patient and NPI mood factor ($\rho = .003, p < .01$) → QOL-AD proxy and patient age ($\rho = .006, p < .01$) → QOL-AD proxy and NPI mood factor ($\rho < .001, p < .001$) MMSE < 21 → QOL-AD patient and NPI mood factor ($\rho = .02, p < .01$) → QOL-AD patient and NPI psychosis factor ($\rho = .03, p < .01$) → QOL-AD proxy and NPI mood factor ($\rho = .004, p < .01$) → QOL-AD proxy and NPI psychosis factor ($\rho < .001, p < .001$)
Ready, Ott, Grace, & Fernandez (2002)	Different stages of dementia (CDR 0-3) PWD: n = 36 MCI ²² : n = 14 Cross sectional study USA	QoL proxy rated Severity of dementia Cognition Patient mood	CBS CDR MMSE Visual Analog Dysphoria Scale (VADS)	→ CBS and CDR ($\rho = -.35, p < .05$) → CBS and VADS ($\rho = .63, p < .01$)

²² Mild cognitive impairment

Table 6: Study characteristics and results of level-1 papers (continued)

Publication	Participants/Study design	Clinical outcome measures	Rating scales	Statistically significant correlations/associations
		Patient QoL ($n = 10$)		
Ready, et al. (2004)	<p>Very mild – mild AD (CDR 0.5-1)</p> <p>PWD: $n = 26$ MCI: $n = 30$ Elderly controls: $n = 23$ Caregiver</p> <p>Cross sectional study</p> <p>USA</p>	<p>QoL patient rated QoL proxy rated Severity of dementia Cognition Depression Behaviours Functioning</p> <p>Patient insight</p> <p>Caregiver depression</p>	<p>DQoL DQoL CDR (correlations not reported) MMSE CSDD NPI-Q (brief version of NPI) The Physical and Self-Maintenance Scale(ADL/IADL) The Clinical Insight Rating Scale (CIR) (Ott & Fogel, 1992)</p> <p>GDS-SF</p>	<p>Analysis based on full sample and not sub-groups:</p> <p>→ DQoL patient negative affect and NPI-Q ($r = .32, p < .01$) → DQoL patient global QoL and NPI-Q ($r = -.31, p < .01$) → DQoL patient self-esteem and IADL ($r = -.37, p < .01$)</p> <p>→ DQoL proxy self-esteem and NPI-Q ($r = -.58, p < .01$) → DQoL proxy positive affect and NPI-Q ($r = -.43, p < .01$) → DQoL proxy negative affect and NPI-Q ($r = .62, p < .01$) → DQoL proxy belonging, global QoL and NPI-Q ($r = -.47, p < .01$) → DQoL proxy self-esteem and MMSE ($r = .48, p < .01$) → DQoL proxy global QoL and MMSE ($r = .31, p < .01$) → DQoL proxy self-esteem, positive affect, belonging, global QoL all strongly negatively correlated with IADL ($p < .01$)</p> <p>→ NPI-Q significant predictor of DQoL patient global QoL ($p < .01$) → NPI-Q highly significant predictor of DQoL proxy self-esteem, positive and negative affect, belonging ($p < .001$) → NPI-Q significant predictor of DQoL global QoL ($p < .01$) → Patient age significant predictor of DQoL proxy belonging ($p < .01$)</p> <p>In post-hoc analyses 4 of 6 DQoL sub-scales correlated significantly with proxies' depressive symptoms (GDS-SF).</p>

Table 6: Study characteristics and results of level-1 papers (*continued*)

Publication	Participants/Study design	Clinical outcome measures	Rating scales	Statistically significant correlations/associations
		Patient QoL ($n = 10$)		
Snow, et al. (2005)	Different stages of dementia PWD: $n = 89$ Caregiver: $n = 89$ Cross sectional study USA	QoL patient rated QoL proxy rated Cognition Depression Agitation Functioning Pain patient rated Pain proxy rated Caregiver depression	QOL-AD QOL-AD Mattis Dementia Rating Scale (DRS) (Mattis, 1988) Ham-D Cohen-Mansfield Agitation Inventory (Cohen-Mansfield, 1986; Cohen-Mansfield, Marx, & Rosenthal, 1989) The Physical and Self-Maintenance Scale (ADL/IADL) Modified Philadelphia Geriatric Center Pain Intensity Scale (Parmelee, Smith, & Katz, 1993) GDS-SF	→ QOL-AD patient and Ham-D ($r = -.41, p < .002$) → QOL-AD patient and pain (patient rated) ($\rho = -.25, p < .05$) → QOL-AD patient and pain (proxy rated) ($\rho = -.25, p < .05$) → QOL-AD proxy and DRS ($r = .27, p < .05$) → QOL-AD proxy and GDS-SF ($r = -.45, p < .002$) → QOL-AD proxy and ADL/IADL ($r = -.36, p < .002$) → Ham-D significant predictor of QOL-AD patient ($p < .002$) → GDS-SF, ADL/IADL ($p < .002$) and Ham-D ($p < .05$) significant predictors of QOL-AD proxy → Agreement between QOL-AD patient and QOL-AD proxy: most significant correlation for social network items: friends, marriage, family ($p < .002$)
Vogel, et al. (2006)	Mild AD (MMSE > 19) PWD: $n = 48$ Caregiver: $n = 45$ Cross sectional study Denmark	QoL patient rated QoL proxy rated Cognition Premorbid intelligence Episodic memory function Depression Patient insight (Anosognosia) Behaviours	QOL-AD, EQ-5D QOL-AD, EQ-5D MMSE Danish Adult Reading Test (DART) (Nelson & O'Connell, 1978) Category Cued Recall (Buschke, Sliwinski, Kuslansky, & Lipton, 1997) GDS Reed's Anosognosia scale (Reed, Jagust, & Coulter, 1993) Frontal Behavioural Inventory (FBI) (Kertesz, 1998)	→ QoL patient rated generally better than QoL proxy rated → Discrepancy in QoL ratings significantly associated with patients' level of insight → QOL-AD/EQ-5D patient and proxy ratings not significantly different between patients with full or impaired insight (level of insight no impact on QoL in mild AD) → QOL-AD proxy and FBI ($r = -.56, p \leq .01$) → EQ-5D proxy and FBI ($r = -.52, p \leq .01$) → EQ-5D patient and GDS ($r = -.41, p \leq .01$) → EQ-5D proxy and GDS ($r = -.50, p \leq .01$)

Table 6: Study characteristics and results of level-1 papers (continued)

Publication	Participants/Study design	Clinical outcome measures	Rating scales	Statistically significant correlations/associations
		<i>Patient and caregiver QoL (n = 2)</i>		
Shin, Carter, Masterman, Fairbanks, & Cummings (2005)	Mild – moderate AD PWD: n = 62 Caregiver: n = 62 Cross sectional study USA	Patient QoL patient rated Patient QoL proxy rated Cognition Behaviours Caregiver QoL Caregiver distress	QOL-AD QOL-AD MMSE NPI QOL-AD NPI-D	→ QOL-AD patient and NPI depression ($r = -.290, p < .05$) → QOL-AD proxy and NPI depression ($r = -.319, p < .05$) → QOL-AD proxy and NPI disinhibition ($r = -.253, p < .05$) → QOL-AD caregiver and NPI agitation/aggression ($r = -.331, p < .01$) → QOL-AD caregiver and NPI anxiety ($r = -.279, p < .05$) → QOL-AD caregiver and NPI disinhibition ($r = -.276, p < .05$) → QOL-AD caregiver and NPI irritability ($r = -.258, p < .05$) → QOL-AD caregiver and NPI total ($r = -.369, p < .01$) → QOL-AD patient money and QOL-AD proxy money ($r = .367, p < .01$) → QOL-AD caregiver and NPI-D agitation/aggression ($r = -.320, p < .05$) → QOL-AD caregiver and NPI-D disinhibition ($r = -.264, p < .05$) → QOL-AD caregiver and NPI-D irritability ($r = -.272, p < .05$) → QOL-AD caregiver and NPI-D total ($r = -.343, p < .01$)

Table 6: Study characteristics and results of level-1 papers (*continued*)

Publication	Participants/Study design	Clinical outcome measures	Rating scales	Statistically significant correlations/associations
		<i>Patient and caregiver QoL (n = 2)</i>		
Thomas, et al. (2006)	<p>Different stages of dementia</p> <p>PWD: <i>n</i> = 100 AD: <i>n</i> = 84 Mixed dementia: <i>n</i> = 9 LBD²³: <i>n</i> = 7 Caregiver: <i>n</i> = 100</p> <p>Cross sectional study</p> <p>France</p>	<p>Patient QoL proxy rated Cognition</p> <p>Execution difficulties in frontal pathologies</p> <p>Depression</p> <p>Behaviours</p> <p>Functioning</p> <p>Caregiver QoL</p> <p>Caregiver depression</p> <p>Formal and informal support</p>	<p>ADRQOL</p> <p>MMSE</p> <p>Frontal assessment Battery (FAB) (Dubois, Slachevsky, Litvan, & Pillon, 2000)</p> <p>CSDD</p> <p>NPI</p> <p>Katz's ADL</p> <p>Dementia-specific QoL scale derived from the first PIXEL studies (Thomas, et al., 2002a, 2002b) and validated in France (Thomas, et al., 2004)</p> <p>Mini-GDS (1-item)</p> <p>Survey based on first PIXEL studies</p>	<p>→ Trend: ADRQOL and CSDD ($\rho = -.514, p = .067$)</p> <p>→ Trend: ADRQOL and NPI ($\rho = -.287, p = .066$)</p> <p>→ ADRQOL and ADL ($\rho = -.991, p = .003$)</p> <p>→ ADRQOL and caregiver QoL ($\rho = .401, p < .001$)</p> <p>→ Caregiver QoL and ADRQOL ($\rho = .268, p = .001$)</p> <p>→ Caregiver QoL significantly different from women to men ($p < .001$)</p> <p>→ Caregiver QoL and NPI total ($\rho = -.486, p = .003$)</p> <p>→ 51% of caregivers depressed; significantly more woman than men</p> <p>→ Mini-GDS and CSDD ($p = .01$)</p> <p>→ Mini-GDS and caregiver QoL ($p = .001$)</p> <p>→ Formal and informal support outcomes not reported</p>

²³ Lewy body dementia

Table 6: Study characteristics and results of level-1 papers (continued)

Publication	Participants/Study design	Clinical outcome measures	Rating scales	Statistically significant correlations/associations
		<i>Conceptual papers (n = 2)</i>		
Ettema, et al.(2005b)	Systematic review Search of MEDLINE, PsychINFO limited to publications in English, Dutch, German	Definition of the concept of QoL applicable to all stages of dementia		<ul style="list-style-type: none"> → QoL domains identified: affect, self-esteem, (appraisal of) physical functioning, social relations, (social) environment, health → Definition of dementia specific QoL: “dementia-specific QoL is the multidimensional evaluation of the person-environment system of the individual, in terms of adaptation to the perceived consequences of the dementia” (p. 366)
Moniz-Cook (2008b)	<ul style="list-style-type: none"> 1. Systematic review: search of PubMed, Web of Science, PsychINFO, EMBASE 2. Consensus workshop with experts from The Netherlands, Germany, Belgium, Ireland, Italy, France, Spain, UK) 3. Web-based pan-European consultation 	European consensus on key domains and outcome measures for psychosocial intervention research in dementia care		<ul style="list-style-type: none"> → 22 measures covering 9 domains: → PWD: QoL, mood, global functioning, behaviour, daily living skills → Family caregiver: mood and burden, incorporating QoL and coping with patient behaviour → Staff: morale, incorporating satisfaction and coping with patient behaviour

In the following sections, a number of clinical patient outcomes are reviewed with regards to their potential as predictors of patient and/or caregiver QoL.

2.3.1.2 Stage of dementia

Even though the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) is often used as an overall staging tool, in its original form it was intended to assess the level of cognitive impairment in PWDs. Three level-1 studies have used the Clinical Dementia Rating Scale to determine the stage of illness in their study population. In only one case (Ready, et al., 2002) was statistical significance of correlations between proxy-ratings of PWDs' QoL and severity of dementia calculated (and established). The other studies (Fuh & Wang, 2006; Ready, et al., 2004) did not report on correlations between QoL and severity of dementia. One study is insufficient from which to draw conclusions regarding the impact of illness severity on PWDs' QoL. More research is needed to determine how the stage of dementia might affect PWDs' QoL, from their point of view as well as their caregivers'.

2.3.1.3 Cognition

All level-1 studies reported the level of cognitive impairment in PWDs. Decreased cognition, however, seems to have had very little influence on patients' QoL. Most studies used both proxy- and self-ratings to assess patients' QoL. Some of those studies observed differences between patient and caregiver ratings of patients' QoL. In these studies, the level of cognitive impairment had an impact on patients' QoL as rated by their family-caregivers. Statistically significant (positive) correlations were found for 2 out of 13 patients' ratings of their own QoL and for 4 out of 18 proxy ratings of patients' QoL. The four studies (Edelman, et al., 2004; Hurt, et al., 2008; Matsui, et al., 2006; Snow, et al., 2005) that reported correlations between cognition and PWDs' QoL seem to support the hypothesis that cognitive impairment has a negative impact on PWDs' QoL mostly from their caregivers' point of view and often only when the impairment becomes more apparent with progressing illness.

In detail, the following observations were made:

For patients at different stages it was found that QoL does not decrease as cognition worsens (Banerjee, et al., 2006; Logsdon, et al., 2002; Ready, et al., 2002). Both, Vogel, et al. (2006), for patients with mild AD, and Fuh and Wang (2006), for patients with mild to moderate AD, found that MMSE scores were not correlated with patients' self- or proxy QoL ratings using the QOL-AD.

In a sample of 93 patients with mild to moderate AD in the USA via two health preference measures, the Euro-QoL-5 domain (EQ-5D) scores ("EuroQol: a new facility for the measurement of health-related quality of life. The EuroQol Group," 1990) and the Health Utilities Index Mark II (HUI:2) (Torrance, et al., 1996) it was found that neither the EQ-5D nor the HUI:2 scores were related to the severity of patients' cognitive impairment (Karlawish, Zbrozek, Kinoshian, Gregory, Ferguson, & Glick, 2008; Karlawish, Zbrozek, Kinoshian, Gregory, Ferguson, Low, et al., 2008).

Some studies observed differences between patient and caregiver ratings of patients' QoL. Using the Dementia Quality of Life Scale (DQoL) (Brod, et al., 1999), Ready and colleagues (2004) found that patients with mild cognitive impairment (MCI) as well as with mild AD reported their own QoL without relation to their MMSE scores. In the same study the proxy reported QoL significantly correlated with the MMSE.

Using the QOL-AD, Hurt, et al. (2008) also determined that patient and caregiver ratings in a European multi-centre study differed: patients' QoL was impacted by their cognitive impairment but only from their caregivers', not from their own, point of view.

There were two exceptions. Firstly, using the Mattis Dementia Rating Scale (a cognitive screening rather than a staging tool) in a sample of persons at different stages of dementia in the USA, Snow, et al. (2005) found statistically significant correlations between measures of cognition and patient rated QOL-AD scores as well as proxy rated QOL-AD scores. Secondly, Matsui and colleagues (2006) determined that for Japanese AD patients with mild impairment (MMSE \geq 21)

the MMSE score was a significant predictor for the total QoL score as measured by the QOL-AD. The same was not true for patients with a MMSE < 21 which could possibly point to a certain level of insight in earlier stages of dementia. Different from other studies, however, caregivers of both groups did not associate the level of cognitive impairment with patients' QoL. Such a discrepancy in relation to other findings might reflect some cultural differences.

2.3.1.4 Depression

The majority of studies (7 out of 12) included patient depression or mood as an outcome. Of seven studies, five assessed both depression as well as neuropsychiatric and behavioural symptoms.

Thorpe and Groulx (2001) reviewed the different types of clinical presentations in which depressive syndromes could occur in dementia :

- Depressive symptoms not fulfilling criteria for specific syndromes,
- Personality changes (such as apathy and passivity),
- Emotional lability and pathological laughing and crying (emotional dysfunction),
- Grieving,
- Dysthymia (depressive symptoms less severe than depressive illness and present for at least 2 years),
- Major depressive disorder,
- Bipolar disorder, depressed phase.

The authors found that depressive syndromes are not only common in dementia but may even be an integral part of the disease development, ranging from isolated symptoms to full depressive disorders (Thorpe & Groulx, 2001).

There is no clear pattern between depression and QoL in PWDs. Of six patient rated QoL measures, three were found to correlate negatively with patient depression measures. Similar inconclusive results were found in the eight studies which investigated depression in relation to patient QoL using both patient and proxy ratings: in 50% of the measures a negative correlation was found between proxy ratings of patient QoL and patient depression. The only pattern

emerging is in studies which included persons at all stages of dementia, where in five out of eight cases a correlation was observed, whereas in studies including only persons with early dementia in only two out of six cases was a correlation reported.

One of the most widely used tools to assess depression in patients with dementia is the Geriatric Depression Scale (GDS) developed by Yesavage, et al. (1982). In the USA, Logsdon and colleagues (2002) found in a sample of AD patients at different stages of the disease that all psychological measures were significantly related to patients' QoL scores. The strongest negative correlations, however, were measured between both patient and caregiver reported QOL-AD ratings of patients' QoL and GDS scores.

Another study conducted in the USA found that in a sample of dementia patients at different severity stages only patients' self rated QoL scores negatively correlated with their GDS scores (Snow, et al., 2005). Caregiver ratings of patients' QoL using the QOL-AD were not associated with patients' depression rates.

In addition to the GDS, a second widely used instrument to assess depression in dementia is the disease-specific Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos, Abrams, Young, & Shamoian, 1988). Using the CSDD in a sample of 100 patients with different progressive dementias (AD, LB, mixed dementia) in France, Thomas and colleagues (2006) reported a significant negative correlation with patients' QoL ratings.

Livingston, Cooper, Woods, Milne and Katona (2008) showed that a raised CSDD score at baseline was a significant predictor of "wellbeing in adversity" as measured by using the patient rated 13th QOL-AD item of overall QoL at the 18 months follow-up.

Studies which did not use dementia-specific QoL instruments also showed a correlation between QoL measures and depression scores. Karlawish, et al. (2008; Karlawish, Zbrozek, Kinoshian, Gregory, Ferguson, Low, et al., 2008) found, for example, in a sample of 93 patients with mild to

moderate AD (MMSE \geq 12) for both health preference measures (the EQ-5D and the HUI:2) that lower preference scores were related to higher depression (GDS) scores.

Although Vogel and colleagues (2006) found no significant correlation between QOL-AD and GDS scores in Danish patients with mild AD, they did find an association between patient/informant rated EQ-5D and GDS scores.

It could be concluded that there is some evidence for an association between patients' QoL and depression, in particular during the later stages of dementia.

It is also difficult to draw conclusions from the literature regarding the correlation between depression and the severity of dementia. In a recent systematic review, Verkaik, Nuyen, Schellevis and Francke (2007) concluded that there was a lack of association between the severity of AD and the prevalence of depressive symptoms in patients. This is supported by a longitudinal study conducted by Zhu, et al. (2008) in the USA on patient dependence and cost changes in AD. Using the Columbia University Scale for Psychopathology in Alzheimer's Disease (Devanand, et al., 1992), the authors found that the prevalence of depressive symptoms fluctuated in the course of 4 years. It could be hypothesised that this fluctuation is the reason for the rather inconclusive results of this review regarding depression in PWDs and PWDs' QoL.

2.3.1.5 Neuropsychiatric and behavioural symptoms

Neuropsychiatric and behavioural symptoms are common manifestations of dementias (Cummings, et al., 1994) and can be grouped into three main syndromes: agitation, psychosis and mood disorders (Ballard, Day, Sharp, Wing, & Sorensen, 2008). More than 80% of people with AD will experience at least one of these symptoms over the course of the illness (Ballard, et al., 2008) including delusions, hallucinations, agitation, anxiety, personality changes, apathy, euphoria, irritability or disinhibition. Neuropsychiatric symptoms may be present before any cognitive changes occur and they change as the dementia progresses, requiring re-evaluation and implementation of new interventions in the course of the illness (Cummings, et al., 1994).

The majority of all level-1 original studies investigated patients' neuropsychiatric and behavioural symptoms in relation to patient QoL.

Most studies reviewed here found significant negative correlations between patients' QoL and the prevalence and/or intensity of neuropsychiatric and behavioural symptoms in dementia. This is especially true for studies that included persons with mild to moderate dementia: four out of six measures correlated with patient ratings of their own QoL and six out of seven measures correlated with proxy ratings of patients' QoL. The results are less conclusive for studies which included persons at all stages of dementia: three out of five measures were negatively correlated with patient QoL.

Neuropsychiatric and behavioural symptoms observed in patients were most often measured by using the Neuropsychiatric Inventory (NPI) (Cummings, et al., 1994). Only one level-1 paper utilised a different tool: Logsdon, et al. (2002) applied the "Revised Memory and Behavior Checklist" (RMBPC) (Teri, et al., 1992) to provide an overall assessment of neuropsychiatric and behavioural symptoms as well as an assessment of specific types of problems, including memory, depression and disruption subscales. For patients' QoL it was found that all three RMBPC subscales negatively correlated with caregiver rated QOL-AD scores, but only the RMBPC depression subscale showed a relationship with patient rated QOL-AD scores (Logsdon, et al., 2002).

Matsui, et al. (2006) found that all NPI factors except the euphoria item negatively correlated with patients' and caregivers' QOL-AD ratings in moderate AD. The same study found that the result was different for patients with mild AD (MMSE < 21): in this group only the 'mood factor', which included apathy and depression/ dysphoria, predicted patients' QoL.

Other studies reported similar findings, (sometimes only for either patient or caregiver ratings) for different dementias. Using the caregiver rated DEMQOL-Proxy (Smith, et al., 2005; Smith, et al., 2007), Banerjee, et al. (2006) found that the total NPI score, as well as several NPI subscores,

(agitation, depression, anxiety, disinhibition, irritability) strongly predicted British patients' QoL in dementia.

Thomas, et al. (2006) also found a relationship between lower patients' QoL ratings, using the proxy rated Alzheimer Disease Related Quality of Life (ADRQL) scale (Rabins, Kasper, & Kleinman, 1999), and higher NPI scores during the PIXEL study in a sample of 100 patients with different progressive dementias.

In a sample of patients with mostly mild to moderate dementia (AD, VD, mixed) from three European countries Hurt, et al. (2008) reported significantly negative correlations between caregiver ratings of patients' QoL and total NPI scores as well as most NPI subscores. When patients rated their own QoL, only the delusion subscale showed a negative correlation with QOL-AD scores.

Ready, et al. (2004) also found in a sample of MCI and mild AD patients in the USA that the results regarding neuropsychiatric and behavioural symptoms as QoL predictors differed depending on patients' or caregivers' perspectives. Using the Neuropsychiatric Inventory Questionnaire (NPI-Q) (Kaufer, et al., 2000), the authors showed that the total NPI-Q score was negatively correlated with patient- and informant-reported global QoL scores. The authors used the Dementia Quality of Life Instrument (DQoL), a disease-specific QoL scale developed by Brod and colleagues containing five domains (Brod, et al., 1999). Total NPI-Q scores also negatively correlated with nearly all proxy but not with patient rated DQoL domains. Only one of the five DQoL domains (negative affect) was correlated with patients' total NPI-Q ratings.

Some studies did not establish a clear correlation between NPI scores and patients' QoL. In a sample of 62 AD patients and their caregivers, Shin and colleagues (2005) found that patients' QoL on both patient and caregiver QOL-AD ratings was negatively correlated with the NPI depression scores and the caregiver rated disinhibition score, but not with any of the other NPI items or total scores.

In a sample of Taiwanese patients with AD, Fuh and Wang (2006) found that NPI scores were not significantly correlated with either patient or caregiver reported QOL-AD scores.

Livingston, et al. (2008) showed that a raised NPI score at baseline was not a significant predictor of “wellbeing in adversity” as measured using the 13th QOL-AD item of overall QoL at 18 months follow-up. Nevertheless, since Livingston and colleagues only used one of the 13 QOL-AD items, the comparability of their investigation into studies that have shown strong correlations between patients’ QoL and NPI scores might be compromised.

Zhu, et al. (2008) did not assess patients’ QoL, but they found that the prevalence of neuropsychiatric and behavioural symptoms in AD patients fluctuated over a 4 year period.

In conclusion, neuropsychiatric and behavioural symptoms clearly impact on patients' QoL in mild to moderate dementia and this view is shared by PWDs and their caregivers.

2.3.1.6 Daily functioning

There are two different domains of patients’ functional competence: basic activities of daily living (ADLs), such as eating, dressing and showering and more complex instrumental activities of daily living (IADLs), such as shopping, finances and using transportation. The majority of level-1 studies (8 of 12) included patients' level of daily functioning as an outcome measure.

In summary, the review did not reveal an obvious pattern explaining how decreasing ADLs/IADLs affect patients’ QoL. Studies with persons at all stages of dementia reported in all four cases a negative correlation between patients' level of functioning and patients' QoL as rated by their caregivers. The same is not true for patient ratings of their own QoL at different stages of dementia. For studies that included persons with only mild to moderate dementia there was hardly any association found between patients’ level daily functioning and patient or proxy ratings of patients' QoL. The only exception is one study which found that PWDs and caregivers agreed that the impairment of IADLs did affect patients' QoL but not the impairment of ADLs.

In detail, the following observations were made:

Using the Physical and Instrumental Self-Maintenance Scale (Lawton & Brody, 1969) in a sample of AD patients at different stages, Logsdon, et al. (2002) found that patient and caregiver QOL-AD ratings were associated significantly with ADL scores but only caregiver QOL-AD proxy-ratings were also correlated with IADL scores.

A similar result was reported by Snow, et al. (2005) who used identical scales to Logsdon, et al. (2002) but in a sample of persons with AD and also with other dementias. The authors did not report results separately for ADLs and IADLs but combined both items into a single composite score. The authors found this composite score to have a high, negative correlation with caregiver QOL-AD rating of patients' QoL but not with patients' self rated QOL-AD scores.

Another study confirms the importance of distinguishing between patient ratings and proxy measures of patients' QoL. Edelman, et al. (2004) used different disease-specific QoL scales and Katz' six-item Activities of Daily Living Scale (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) in a sample of 54 day care clients in the USA. Analysing a sub-sample of 36 mild to moderate cognitively impaired clients, the authors found no association between clients' QoL rating and the level of impairment of ADLs. However, when Edelman, et al. (2004) used the full sample, including people at all stages of dementia and asked staff to rate clients' QoL, a moderate to strong correlation with clients' functional impairment was found.

Utilising the "Alzheimer's Disease Co-operative Study Inventory" (Galasko, et al., 1997), Livingston, et al. (2008) reported that more impaired ADL functioning at baseline was a significant predictor of patients' "wellbeing in adversity" ratings.

In agreement with the above studies, Ready, et al. (2004) reported that for a mixed sample of participants with MCI and AD the impairment in IADLs was associated only with lower patient

reported self-esteem (DQoL scale). Most of the caregiver rated QoL domains, however, were correlated with patients' level of functional impairment.

Similarly, the PIXEL study (Thomas, et al., 2006) found in a sample of persons with different dementias a strong negative correlation between proxy rated ADRQOL scores and the level of impairment of ADLs.

Using a non-dementia specific instrument to measure QoL as part of the Odense study in Denmark, Andersen, Wittrup-Jensen, Lolk, Andersen and Kragh-Sorensen (2004) found that patients' dependency status, as defined by their ability to perform ADLs/IADLs, was the most important factor which affected patients' HRQoL.

Some research found no association between patients' QoL and the level of patients' functional impairment. Two of the studies are comparable in their populations and measurements. Both examined the QoL of persons with AD by administering the QOL-AD to patients and to their caregivers. The first study was conducted by Matsui, et al. (2006) in Japan in 2006 in a sample of 140 patients with mild to moderate AD. The authors used the Hyogo Activities of Daily Living Scale (HADL) (Hironon, Yamadori, Mori, Yamashita, & Tokimasa, 1995) to measure ADLs and IADLs. The level of functional impairment was not a predictor of patient or caregiver rated QoL, neither for the group of patients with mild cognitive impairment (MMSE score ≥ 21) nor for the group of patients with moderate cognitive impairment (MMSE score < 21 , > 10). Matsui, et al. (2006) observed that their findings differed from other studies because, in the early to moderate stages, neuropsychiatric symptoms might have been perceived by patients and their caregivers as being a more significant component of patients' QoL rather than functional impairment.

Similar results were reported by Fuh and Wang (2006) from a Taiwanese sample of AD patients with a MMSE score of more than 10 points. Using the Blessed Dementia Rating Scale (Blessed, Tomlinson, & Roth, 1968), the authors did not find ADL scores to be a significant predictor of PWDs' QoL.

Banerjee, et al. (2006), who had included participants with different dementias in their study, also found no correlation between patients' QoL and patients' functional limitation as measured by the DEMQOL-Proxy and the Barthel Index (Gompertz, Pound, & Ebrahim, 1994). Given the tendency for association between functional impairment and proxy ratings of patients' QoL, this is a surprising result which does not seem to fit into the emerging pattern. On the other hand, Banerjee, et al. had included persons with mild to moderate dementia. The association between functional impairment and patients' QoL seems to be stronger for people at the more advanced stages of dementia.

Non-dementia specific QoL scales showed a variety of outcomes. Karlawish, et al. (2008; Karlawish, Zbrozek, Kinoshian, Gregory, Ferguson, Low, et al., 2008) found in a sample of 93 patients with mild to moderate AD for both the EQ-5D and the HUI:2 (which are both patient rated) the expected association between lower health preference scores and greater patient reported impairment for the IADLs. When patients rated their ADLs, the scores were associated with the HUI:2 but not with the EQ-5D. No correlation was found between health preference scores and patients' functional impairment as rated by their caregivers. Only lower HUI:2 ratings showed a trend of being associated with lower caregiver ratings of patients' ADLs and IADLs. Karlawish, Zbrozek, Kinoshian, Gregory, Ferguson and Glick (2008) concluded that patients' reports of disability were legitimate self-perceptions of daily functioning but that the reports might have been associated with comorbidities rather than with AD.

In conclusion, the loss of more complicated abilities of daily living, such as shopping, does seem to have an impact on patients' QoL already at an early stage of illness. Caregivers notice the progressing impairment in patients' daily functioning and from their point of view this clearly impacts negatively on patients' QoL at a later stage.

2.3.1.7 Health

Three of the reviewed studies assessed the general health of PWDs (all in the USA). One (Edelman, et al., 2004) reported the findings regarding patients' comorbidities only in a descriptive analysis and not in relation to QoL measures. The other two studies included persons at all stages of dementia and found negative correlations with patients' QoL (patient and proxy rated): one assessed PWDs' physical health (Logsdon, et al., 2002), whilst the other assessed patients' pain (Snow, et al., 2005).

Therefore, it seems important also to consider patients' general physical health in addition to their dementia when assessing patients' QoL.

2.3.2 Clinical measures of caregiver quality of life

Family caregivers are the primary base of support for people with dementia. Most people with dementia receive care at home, generally provided by a female caregiver, usually a spouse or daughter (Access Economics, 2006). Caregivers experience adverse psychological, physical, social, and financial consequences, such as higher rates of depression, poorer physical health than non-caregivers, social isolation, and direct and indirect financial costs (Brodaty, et al., 2003). The literature review identified two original studies which used a disease-specific instrument to measure the QoL of informal caregivers of PWDs and which were graded level-1 studies.

2.3.2.1 Caregiver quality of life per se

Researchers can choose from a variety of different tools to assess QoL of caregivers. Nevertheless, most of these tools are not specifically designed to assess QoL of caregivers of PWD. Some of the most commonly used scales are the 30-item or 12-item General Health Questionnaire (GHQ-30/GHQ-12) (Goldberg, McDowell, & Newell, 1972), the EQ-5D, Medical Outcomes Study 36-item or 12-item Short-Form (SF-36/SF-12) (Ware, 1993; Ware, Kosinski, & Keller, 1996) and the HUI:2.

Using both the SF-36 and the HUI:2 in a large population of 679 caregivers of people with AD, Bell, Araki and Neumann (2001) concluded that generic preference-weighted instruments may not

adequately reflect HRQoL in such a population, thus requiring the development of condition-specific instrument. Seven years later, however, the author was still only able to identify two level-1 studies which had used disease-specific assessment tools (Shin, et al., 2005; Thomas, et al., 2006). Both studies found no significant association between caregivers' QoL and patients' cognition, but both studies showed the obvious negative impact of neuropsychiatric and behavioural symptoms on caregivers' QoL. Caregivers' QoL not only decreased with increased prevalence and/or intensity of PWDs' neuropsychiatric and behavioural symptoms but also with a higher level of distress caused by those symptoms.

For the relation between patient and caregiver QoL the results were less evident. One of two studies to use a disease-specific instrument was conducted by Thomas, et al. (2006). Including 100 caregivers of patients with AD ($n = 84$), mixed dementia and Lewy bodies dementia (LBD) at all stages of illness the authors found that caregivers' QoL was significantly related to patients' QoL and negatively to the NPI global score. Interestingly the authors also found that caregivers' QoL improved the longer the illness proceeded and that women reported a worse QoL than men.

Shin, et al. (2005) also used a dementia-specific instrument (QOL-AD) to measure caregivers' QoL of 62 AD patients and found that caregiver QOL-AD scores were negatively correlated with agitation/aggression, anxiety, disinhibition, irritability/lability and total NPI scores.

Serrano-Aguilar, Lopez-Bastida and Yanes-Lopez (2006) assessed the HRQoL and perceived burden of 237 caregivers of AD patients at different stages of the illness in Spain and found that higher feelings of burden, more time committed to care and older age were variables that impacted on caregivers' HRQoL. The analysis showed that caregivers had a higher frequency of problems for each EQ-5D dimension (mobility, personal care, daily activities, pain and anxiety/depression) and a lower general health status than the general population.

Another study, conducted in Spain, found that PWDs who were cared for by relatives who rated their own health as being "much worse" compared to the previous year using the SF-36 had a six

times higher risk of being admitted to a nursing home within 12 months (Argimon, Limon, Vila, & Cabezas, 2005).

Using a generic QoL instrument in 207 caregivers of PWDs in Belgium, Kurz, et al. (2003) found that health scores were worse for this cohort compared to caregivers of patients with cognitive impairment but without dementia (for example MCI patients) and scores were worst for caregivers of patients with severe dementia. Nevertheless, other outcomes in the same study (SF-36 mental component score, depression, sense of competence) showed that caregivers living with patients with severe dementia had generally a better QoL than those living with patients with moderate dementia. The authors speculated if this could be due to the progression of the disease and the lack of patient's recognition resulting in decreasing concern of caregivers with their role.

In contrast to these results, Lopez-Bastida, Serrano-Aguilar, Perestelo- Perez and Oliva-Moreno (2006) did not find a correlation between the degree of severity of AD and caregiver QoL using the EQ-5D in a mailed questionnaire.

Markowitz, Gutterman, Sadik and Papadopoulos (2003) also used a mailed survey but in a very large sample of more than 2000 caregivers of AD patients in the USA to assess participants' HRQoL. The result showed that compared to a normative, age-adjusted sample, caregivers had lower mental and physical scores (SF-12). Poorer caregiver mental health was associated with patient depression and disruptive behaviour (RMBPC), recent patient hospitalisation, emergency visits and more hours of caregiving. Increased patient disruptive behaviour and recent hospitalisation were, in addition to a negative view of patient's medical care, also linked to lower physical caregiver health.

Banerjee, et al. (2006) found a correlation between decreased patients' QoL and caregivers' poorer mental health (GHQ-12).

It can be concluded that, similar to patients' own QoL ratings, cognition alone does not affect caregivers' QoL, but at a later stage the level of cognitive impairment might predict how caregivers evaluate patients' QoL.

2.3.2.2 Burden and distress

The only two studies which assessed caregivers' QoL using a dementia-specific questionnaire both evidently demonstrated the impact of dementia on caregivers. Shin and colleagues (2005) found a strong negative correlation between caregiver QoL and caregiver distress, measured using the NPI-Caregiver Distress Scale (NPI-D) (1998) which assesses the caregiver's response to each type of behaviour. The other study (Thomas, et al., 2006) measured caregiver depression and found a strong relation with caregivers' QoL ratings. In addition, three level-1 studies measuring only patients' QoL found that in all four cases the proxy ratings were significantly related to caregivers' levels of distress or burden. In 75% of the measures patients' self rated QoL was also associated with caregiver distress or burden. It can be concluded that the QoL of caregivers of PWDs is influenced by levels of distress caused by patients' neuropsychiatric and behavioural symptoms. Also, the more burdened and distressed caregivers feel the lower they rate patients' QoL and the lower patients rate their own QoL.

Furthermore, Donaldson, Tarrier, & Burns (1998) found that depression and behavioural disturbances in British patients were significant predictors of burden in caregivers on Gilleard's Strain Scale (Gilleard, 1984), with patient depression (CSDD) as the strongest predictor of caregiver distress as measured using the General Health Questionnaire (Goldberg, 1978).

A study conducted in Spain found that higher levels of burden as measured with the Zarit Burden Interview (Zarit BI) (Zarit, Reever, & Bach-Peterson, 1980) were associated with lower HRQoL (using the EQ-5D), lower education of the caregivers, increased caregiver age and family relationship with lower levels of burden observed in sons and daughters compared to partner or others (Serrano-Aguilar, et al., 2006).

Coen, O'Boyle, Coakley and Lawlor (2002) found in Ireland that daughters were overrepresented in the higher burden group (Zarit BI) as compared to the lower burden group. Also, caregivers in the higher burden group had poorer QoL, as measured with the Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW) (Hickey, et al., 1996) and well-being (GHQ-30), and cared for patients with more behavioural disturbances.

Logsdon, et al. (2002) found that caregivers' subjective and objective burden scores were negatively correlated with both patient and caregiver ratings of patient QOL-AD scores.

In contrast, Fuh and Wang (2006) did not find the NPI-D score to be correlated with patients' QOL-AD scores but the distress score was the only significant predictor of the variance between patient rated QoL and caregiver ratings of patients' QoL.

Karlawish, Casarett, Klocinski and Clark (2001) concluded that in addition to caregivers' experience of burden, depression in caregivers as well as the illness severity negatively influenced caregiver ratings of patients' QoL.

2.3.2.3 Depression

One (Thomas, et al., 2006) of the two level-1 papers which assessed not only patient but also caregiver QoL found a strong negative correlation with caregiver depression, which means that depressive symptoms in caregivers strongly predicted how caregivers rated their own QoL. Additionally, four level-1 studies measured caregiver depression (or caregiver mental health) without assessing caregiver QoL. These studies found that depressive symptoms did not impact on how patients rated their own QoL, but in 75% of the measures depressed caregivers rated patients' QoL lower than non-depressed caregivers. It can be concluded that caregivers who are depressed have a poorer QoL and rate the QoL of PWDs lower than non-depressed caregivers.

Also, a number of level-1 studies have used the short version of the GDS (Sheikh & Yesavage, 1986) to assess depressive symptoms in caregivers, with different results. Ready, et al. (2004) found that AD caregivers' GDS-15 scores were not significantly correlated with any of the patient

or caregiver reported outcomes, whereas Snow and colleagues (2005) did report an association between higher dementia caregiver ratings of patient QoL and lower caregiver depression.

Using generic QoL scales to assess patient QoL and the GDS-15, two more studies support Snow's findings: both studies were conducted by Karlawish and colleagues in patients the majority of whom had mild to moderate AD (2008; Karlawish, Zbrozek, Kinoshian, Gregory, Ferguson, Low, et al., 2008).

Covinsky, et al. (2003) also applied the GDS-15 to a large sample of 5627 patients with moderate to advanced dementia and their primary caregivers in the USA. The authors found that 32 % of caregivers had to be classified as depressed, which was predicted by a variety of factors: taking care of patients younger than 65 years, being less educated, patients' ADL dependency and angry or aggressive behaviours. Independent caregiver predictors of depression included low income, being a spouse or daughter of the patient, spending more hours of caregiving and having worse physical functioning.

Thomas, et al. (2006) not only found that women had a worse QoL than men but women were also more often depressed than men. The same study showed that caregivers' depression was frequently associated with patients' depression.

Using the short-form Beck Depression Inventory (Beck & Beck, 1972; Knight, 1984) in 207 caregivers of PWDs, Kurz, et al. (2003) found that this cohort more often had signs of depression compared to caregivers of patients with cognitive impairment but without dementia. The authors also found that among those with depression, caregivers of demented patients more often were moderately or severely depressed. These figures also increased with severity of dementia except for caregivers of patients with severe dementia.

2.3.3 Formal supports and interventions

The author identified 274 articles when systematically searching the literature databases using the keywords "quality of life", "dementia" and "formal support/intervention". The majority of relevant

articles were published in the past 10 to 15 years, reflecting a growing interest in the topic of dementia and available supports for patients and their caregivers. Bartlett, Gray, Byrne, Travers and Lui (2007) explained:

Over the past decade, there has been a growing consensus among policy makers of the importance of providing flexible and person-centred forms of care for older people. In the case of dementia care, the rising importance of a 'person-' or 'client-centred' approach redirects the focus of service from concern with arresting cognitive decline and controlling behavioural symptoms to preventing excess disability and promoting well-being and quality of life of people with the illness. (p. 165)

It has been shown that services available to patients and caregivers are not always utilised most effectively. It seems a paradox that caregivers who would possibly benefit the most from an intervention might actually not use services available to them. Biegel, Bass, Schulz and Morycz (1993) found that caregivers of patients with mild to moderate dementia in the USA were less likely to use services at all or to use services beyond in-home care if they had inadequate informal support, were more emotionally distressed and cared for functionally more impaired patients. Vetter, et al. (1998) were surprised by the low rate of utilisation amongst participants of a study conducted in Germany: fewer than one-third of AD patients and their caregivers utilised the available supports and interventions. The authors also reported that the main reason for low service utilisation was "poor knowledge regarding the availability of homecare supports" (p. 111). Of all 274 articles identified, seven were graded level-1 papers, summarised in **Table 7** (p. 68). Six of these publications investigated non-pharmacological supports and interventions for PWDs and their caregivers. Only one pharmacological study fulfilled the criteria to be graded as a level-1 publication.

Table 7: Formal support and intervention level-1 papers

Publication	Intervention and study design	Participants	Clinical outcome measures ²⁴	Rating scales	Outcomes
			<i>Pharmacological interventions (n = 1)</i>		
Aisen, et al. (2003)	Rofecoxib or naproxen vs. placebo Randomised, double-blind, placebo controlled, parallel group, multi-centre trial 1 year exposure to medications	Mild – moderate AD PWD ²⁵ : n = 351 Rofecoxib: n = 122 Naproxen: n = 118 Placebo: n = 111 USA	Cognition QoL ²⁶ patient rated Severity of illness Behaviour	Alzheimer Disease Assessment Scale-Cognitive (ADAS-Cog) subscale (Rosen, Mohs, & Davis, 1984) QOL-AD CDR NPI	No significant differences between treatment- and placebo groups.
			<i>Non-pharmacological interventions (n = 6)</i>		
Banerjee, et al. (2007)	Evaluation of the Croydon Memory Service Model: early diagnosis and support for PWDs and their caregivers Prospective cohort study 6-month follow-up and qualitative methods	Mild – severe dementia PWD: n = 141 (at 6-month follow-up) AD: n = 64 VD ²⁷ : n = 4 mixed dementia: n = 36 Other neurological illness: n = 3 No illness: n = 34 UK	Cognition QoL patient rated QoL proxy rated Depression Behaviour ADL	MMSE DEMQOL DEMQOL-Proxy GDS-15 NPI BADL	At 6-month follow-up, those referred to the service had statistically significant increased QoL (self- and proxy rated) and decreased behavioural symptoms compared to baseline. Also, marginal improvement in depression.

²⁴ All outcomes are patient related unless stated otherwise.²⁵ Person with dementia²⁶ Quality of life²⁷ Vascular dementia

Table 7: Formal support and intervention level-1 papers (*continued*)

Publication	Intervention and study design	Participants	Clinical outcome measures	Rating scales	Outcomes
			<i>Non-pharmacological interventions (n = 6)</i>		
Droes, Meiland, Schmitz, & van Tilburg (2004)	Combined information/support for PWDs and caregivers plus day care vs. day care only Pretest-posttest control group study 7-month follow-up	Mild - severe dementia PWD: n = 73 (at 7-month follow-up) Intervention group: AD: n = 42 VD: n = 7 Mixed dementia: n = 8 Other neurological illness: n = 10 Control group: n = 16 Caregiver: n = 73 Netherlands	Severity of dementia Cognition QoL patient rated Mood Depression Behaviour Functioning (need of care, severity of impairment, change in 'physical disability') Caregivers' feeling of competence	Reisberg's Global Deterioration Scale (Dutch version) (Muskens, 1993; Reisberg, 1983) MMSE DQoL Philadelphia Geriatric Centre Morale Scale (Dutch version) (Droes, 1991; Lawton, 1975; Ryden & Knopman, 1989) CSDD (Dutch version) (Droes, 1996) subscales 2 and 4 of the Assessment Scale for Elderly Patients (Van der Kam, Mol, & Wimmers, 1971), subscale 1 of the Observation Scale for Intramural Psychogeriatrics (Verstraten & van Eekelen, 1987) Subscale 'In need of care' and '3A' of the Assessment Scale for Elderly Patients, Reisberg's Global Deterioration Scale Feeling of Competence Scale (modified version) (Teunisse & de Haan, 1994)	Intervention group at 7-month follow-up had better behaviour and mood outcomes (lower scores): inactivity, non-social behaviour, total number of behaviours, depressive behaviour. Intervention group was also statistically significant different from control group on the subscale 'self-esteem' of the DQoL.

Table 7: Formal support and intervention level-1 papers (*continued*)

Publication	Intervention and study design	Participants	Clinical outcome measures	Rating scales	Outcomes
			<i>Non-pharmacological interventions (n = 6)</i>		
Gitlin, et al. (2008)	Tailored Activities Program (occupational therapeutic intervention) Prospective 2-group (treatment, wait-list control) randomised controlled pilot study 4-month follow-up	Moderate - severe dementia (MMSE < 24) PWD: n = 56 (at 4-month follow-up) Intervention group: n = 29 Control group: n = 27 USA	Cognition QoL proxy rated Depression Behaviour (frequency of occurrence) Caregiver subjective burden Caregiver depression Caregiver confidence Caregiver skill enhancement	MMSE QOL-AD CSDD Agitated Behaviors in Dementia Scale (Logsdon, Teri, et al., 1999), RMBPC Zarit BI CES-D scale (Radloff, 1977) self developed questionnaire Task Management Strategy Index (Gitlin, et al., 2002)	Intervention group reported reduced frequency of problem behaviours, fewer hours spent on informal caregiving tasks, greater confidence and skill improvement compared to wait list controls. No impact on patients' QoL or depressive symptoms. Depressed and non-depressed caregivers benefited from intervention.
Graff, et al. (2007)	Community occupational therapy Randomised controlled trial 6 and 12 weeks follow-up	Mild - moderate dementia PWD: n = 114/105 (at 6/12 weeks follow-up) Intervention group: n = 58/53 Control group: n = 56/52 Netherlands	Cognition QoL patient rated Depression Health status Caregiver QoL Caregiver depression Caregiver health status	MMSE DQoL CSDD GHQ-12 DQoL CES-D GHQ-12	All overall outcome scores were statistically significantly better in the intervention group than in the control group at 6 and 12 weeks follow-up. The caregiver QoL subscales 'negative affect' and 'positive affect' did not maintain their significant benefit over time.

Table 7: Formal support and intervention level-1 papers (*continued*)

Publication	Intervention and study design	Participants	Clinical outcome measures	Rating scales	Outcomes
			<i>Non-pharmacological interventions (n = 6)</i>		
Teri, McCurry, Logsdon, and Gibbons (2005)	<p>Training of community consultants to teach caregivers a behavioural approach to mood and problem behaviour in PWDs</p> <p>Randomised controlled trial</p> <p>Pretest-posttest design</p> <p>3 and 6 months follow-up</p>	<p>Community health care professionals with at least 1 year of clinical experience with elderly persons: <i>n</i> = 6</p> <p>AD at different stages</p> <p>PWD: <i>n</i> = 83/66 (at 3/6 months follow-up)</p> <p>Intervention group: <i>n</i> = 42/32</p> <p>Control group: <i>n</i> = 41/34</p> <p>USA</p>	<p>Cognition</p> <p>QoL patient rated</p> <p>QoL proxy rated</p> <p>Behaviour</p> <p>Caregiver QoL</p> <p>Caregiver depression</p> <p>Caregiver sleep quality</p> <p>Caregiver stress</p> <p>Caregiver burden</p> <p>Caregiver feeling of competence</p>	<p>MMSE</p> <p>QOL-AD</p> <p>QOL-AD</p> <p>NPI, RMBPC</p> <p>QOL-AD</p> <p>CES-D, HDRS</p> <p>Caregiver Sleep Questionnaire (McCurry & Teri, 1996)</p> <p>Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983)</p> <p>Screen for Caregiver Burden</p> <p>Short Sense of Competence Questionnaire (SSCQ) (Vernooij-Dassen, et al., 1999)</p>	<p>Caregivers who received the training showed significant greater reductions in most outcomes compared to the control group: depression, burden and reactivity to difficult behaviours.</p> <p>Patients' QOL-AD scores were rated higher by caregivers in the intervention group.</p> <p>Patients' frequency and severity of difficult behaviours was also reduced in the intervention group.</p> <p>All results were maintained at 6-month follow-up.</p>

Table 7: Formal support and intervention level-1 papers (*continued*)

Publication	Intervention and study design	Participants	Clinical outcome measures	Rating scales	Outcomes
			<i>Non-pharmacological interventions (n = 6)</i>		
Woods, et al. (2005) Cochrane Review	Systematic literature review regarding reminiscence-therapy in dementia	<p>Dementia at different stages</p> <p>Caregivers</p> <p>Outcome measures included in review: Cognition Patient QoL/well-being Communication and interaction</p> <p>Impact on informal and formal caregiver (for example, caregiver strain, staff knowledge regarding PWD...)</p>	<p>Data from four trials were included: Statistically significant results for cognition, mood, general behaviour, caregiver strain, staff knowledge.</p> <p>One of the four trials (Thorgrimsen, Schweitzer, & Orrell, 2002): QoL patient rated QoL caregiver rated</p>	<p>Thorgrimsen, Schweitzer, & Orrell, 2002: PWD: <i>n</i> = 11 Caregivers: <i>n</i> = 11</p> <p>Intervention group: PWD: <i>n</i> = 7, caregiver <i>n</i> = 7 Control group: PWD: <i>n</i> = 4, Caregivers: <i>n</i> = 4</p>	<p>Number of participants in all four trials was too small and quality not good enough to draw conclusions from.</p> <p>But, Woods, et al. (2005) found a number of promising indications for the efficacy of reminiscence-therapy in dementia.</p>

This section summarises research findings from studies in the area of formal supports available to patients with dementia and their caregivers. It covers the following types of interventions: pharmacological treatment (2.3.3.2, p. 75), complementary therapies (2.3.3.3, p. 79), interventions to promote health, well-being and cognitive functioning (2.3.3.4.1, p. 81), education (2.3.3.4.2, p. 86), counselling (2.3.3.4.3, p. 88), respite care (2.3.3.4.4, p. 90) and multi-component interventions (2.3.3.4.5, p. 92). Amongst the papers that were included for this review the author also identified two systematic reviews which were graded level-2 papers (Schulz, et al., 2002; C. Thompson, et al., 2007). These two reviews, together with three other meta-analyses (which were excluded from the actual review), are discussed in the following overview of available formal interventions.

2.3.3.1 Overview

A meta-analysis of 34 psychosocial interventions for caregivers of people with dementia (from 30 studies) found significant benefits in caregiver psychological distress, caregiver knowledge of the disease and patient mood, but not in caregiver burden. Brodaty, et al. (2003) also found that interventions were more likely to be successful if not only caregivers but patients were involved as well. Additionally, the authors identified four of seven studies where interventions had resulted in delayed nursing home admissions. Brodaty, et al. (2003) concluded that some caregiver interventions can reduce caregiver psychological morbidity and help PWDs to stay at home longer. Schulz, et al. (2002) reviewed a wide range of intervention studies, published between 1996 and 2001, in order to identify psychosocial and pharmacological interventions that focus on clinically significant care outcomes. Even though the authors identified five studies that assessed QoL, the assessment scales used in these studies were not dementia-specific, and the review was therefore graded a level-2 paper. Schulz, et al. (2002) reported that of these five studies, two interventions showed a positive effect and three had no statistically significant effect on participants' QoL outcomes. The only QoL study, rated by the authors as having a clinically meaningful outcome, was conducted by Zanetti, Metitieri, Bianchetti and Trabucchi (1998), where caregivers of the

intervention group (education and support) improved their satisfaction with life by 12.8% whereas the control group did not. Overall, Schulz, et al. (2002) found that many studies had reported a small to moderate effectiveness on a broad range of outcomes, but only a small proportion of these studies had achieved clinically meaningful outcomes. Nevertheless, the authors emphasised that caregiving interventions had shown increasing impact on outcomes such as service utilisation and psychiatric symptoms including depression, and that intervention services were highly valued by caregivers.

In a later systematic review of 41 randomised controlled trials published between 1999 and 2005, Schulz, Martire and Klinger (2005) found that most interventions for caregivers of PWDs consisted of more than one component, often combining educational materials with counselling or skill training. About half of the included studies (20 of 41) showed small but statistically significant effects of psychosocial interventions on caregivers and/or patients. The studies without statistically significant results tended to include only caregivers and provided no psychosocial treatment to patients while assessing outcomes that were patient-focussed, like memory impairment. Of all 41 studies included, only one intervention was assessed with QoL as an outcome measure (Fung & Chien, 2002). Using a non-dementia specific QoL scale, Fung and Chien found that caregivers in the intervention group (12 1-hour weekly sessions of education, psychological support and problem solving) improved their distress levels and QoL more than control group caregivers who only received conventional services (in Hong Kong).

The fourth systematic review was conducted only recently by Thompson, et al. (2007) and included 44 studies from the Specialised Register of the Cochrane Dementia and Cognitive Improvement Group. The authors found statistically significant positive effects of support groups on caregivers' depressive symptoms. Nevertheless, the authors were cautious when interpreting these findings because of the factors that have been shown to impact on depression (such as burden) but were often not measured, and because of the poor average quality of the included studies with small numbers of participants and short follow-up periods. Thompson, et al. (2007)

found no evidence for the efficacy of information and support interventions on any of the other caregiver outcomes, including burden.

Finally, the most recent review with a focus on formal interventions in dementia concluded that available pharmacological interventions have proven to have a moderate positive impact on symptoms of dementia which could be enhanced through psychosocial interventions (Saddichha & Pandey, 2008).

2.3.3.2 Pharmacological treatments

Despite the fact that dementia cannot be cured there is a variety of different medications available to treat the symptoms of dementia. There is evidence that cholinesterase inhibitors (ChEIs) can improve some of the symptoms but they cannot slow down the disease progression (Bartlett, et al., 2007). AD is associated with reduced levels of the neurotransmitter acetylcholine. To increase the level of this neurotransmitter in patients, ChEIs can be given, which has proven to reduce acetylcholinesterase, an enzyme responsible for the destruction of acetylcholine. By destroying the enzyme acetylcholinesterase, the concentrations of acetylcholine in central synapses can be increased, which is believed to be responsible for the positive impact on patients' symptoms observed during trials (Bartlett, et al., 2007). Three ChEIs (donepezil, rivastagmine, galantamine) as well as a fourth drug, memantine, are available in New Zealand to treat dementia. Memantine "is a non-competitive n-methyl-D-aspartate (NMDA) receptor inhibitor that blocks the excessive release of glutamate and thereby preventing the influx of calcium ions which thought to be associated with neuronal degeneration" (Bartlett, et al., 2007). Even though all four drugs are available, they are not subsidised. The only possibility to obtain funding for these medications in New Zealand is by applying for a disability allowance. But, since PWDs have a high risk for comorbidities causing additional costs (Kuo, Zhao, Weir, Kramer, & Ash, 2008), this fund often has to cover a wide range of services leaving little to nothing for the dementia drugs.

No level-1 papers were identified regarding ChEIs in dementia; that is, QoL has not been assessed in ChEIs trials by using a dementia-specific QoL scale. The only pharmacological study graded level-

1 investigated the effect of rofecoxib or naproxen versus a placebo regarding patient cognition, QoL, severity of dementia and neuropsychiatric and behavioural symptoms, and found no significant differences between treatment and placebo groups.

In studies where QoL was measured, using a generic assessment tool, no improvements regarding QoL *per se* were observed. Based on a number of level-2 publications, however, it could be concluded that ChEIs might have a positive impact on patients' cognitive and daily functioning, particularly in mild to moderate dementia.

The following section discusses all level-2 papers which assessed the efficacy of ChEIs regarding QoL in dementia using non-dementia specific QoL scales. Some papers were also graded level-2 and are discussed below if they assessed the efficacy of ChEIs not regarding QoL *per se*, but regarding other aspects of QoL. Cochrane Reviews which explicitly stated QoL as an outcome measure but which were not able to identify any papers fulfilling this criterion were also graded as level-2 papers and are discussed in the following section.

Burns et al. (1999) assessed the effects of donepezil, including a patient rated QoL measurement, but the authors applied a scale which has not been validated for the use dementia. In this multinational RCT, more than 800 patients with mild to moderate AD were enrolled and improvements were observed in patients' cognition and global function but not in QoL.

A systematic review of the clinical and cost-effectiveness of donepezil, rivastagmine and galantamine for AD was conducted by Clegg and colleagues (2001) and updated 1 year later by the same authors (Clegg, et al., 2002). Based on studies which did not use dementia-specific QoL assessment tools, the authors found that there was limited effect of the three dementia-medications, or in some instances a deterioration in QoL. It should be noted that Clegg, et al. (2001) did identify one systematic review by Birks, Melzer and Beppu (2000) regarding donepezil in AD which had included a study that had used the dementia-specific Progressive Deterioration Scale (PDS) (DeJong, Osterlund, & Roy, 1989). Clegg, et al. (2001) summarised the results of Birks,

et al.'s review by saying that there was no evidence of difference in donepezil compared to placebo on a patient rated QoL scale (p. 10). But in their review Birks, et al. (2000) pointed out that even though the PDS had been developed as a dementia-specific QoL scale on account of the correlation between ability to perform ADLs and QoL, the scale did actually measure changes in 29 items of ADLs and not QoL. The authors therefore had not included the study which had used the PDS as a study with a QoL outcome, but with ADLs. The author followed Birks' and colleagues' approach and therefore rated the review conducted by Clegg, et al. (2001) as a level-2 paper. In their update, Clegg, et al. (2002) did not identify any additional pharmacological study regarding QoL as an outcome measure in their update and the paper was graded level-2.

Birks and Harvey (2006) also updated the review on donepezil and found that the medication is beneficial for people at all stages of AD, being associated with improvements in cognitive and daily functioning. But the authors found no evidence of an effect on patients' QoL, although the scale used was unvalidated for PWDs.

These findings are supported by a second systematic review conducted the same year but including not only donepezil but rivastagmine and galantamine as well (Takeda, et al., 2006). Takeda and colleagues found that all three ChEIs could delay cognitive impairment in patients with mild to moderately severe AD for at least 6 months duration. The review did not identify any study with QoL as an outcome measure in addition to the ones already included by Clegg, et al. (2001, 2002)

Donepezil showed similar effects in VD. Cognitive functioning, clinical global impression and ADLs improved in patients with mild to moderate VD (Malouf & Birks, 2004).

In a recent review, regarding the effectiveness of cholinesterase inhibitors and memantine, Raina, et al. (2008) found for all four medications consistent effects in cognition and global assessment. The authors also found that behavioural and QoL outcomes were evaluated less frequently and

showed less consistency than cognition and global patient outcomes. No additional study which included a QoL assessment was identified by Raina and colleagues.

The database searches identified only one publication regarding pharmacological interventions others than ChEIs which explicitly assessed QoL using a disease-specific scale (Aisen, et al., 2003). The authors found that treatment with the anti-inflammatory drugs rofecoxib or naproxen had no significant effect on the NPI or QOL-AD scores in a randomised controlled trial (RCT) of 474 treated participants with mild to moderate AD after 1-year exposure to medications.

Other possible treatments include atypical antipsychotics such as risperidone. The treatment with antipsychotics is very common in clinical practice and therefore one study and one systematic review have been discussed here, even though neither of the two publications included QoL as an outcome measure. Arriola, Diago, Buron and Gallego (2005) found that risperidone significantly improved behavioural and psychological symptoms, especially agitation/aggression and sleep disturbances, and also reduced caregiver burden as measured using the NPI and NIP-D.

The Cochrane Collaboration (Ballard & Waite, 2006) only recently reviewed the effects of atypical antipsychotics for aggression and psychosis in patients with AD and found that there was significant improvement of aggression and psychosis in patients treated with risperidone and of aggression in patients treated with olanzapine in comparison to placebo. But the authors also reported an elevated risk for serious adverse effects including cerebrovascular events (for example stroke), mortality and oedema. It was concluded that antipsychotics have a modest efficacy but the higher risk for adverse reactions was a concern and the drugs were not recommended to be prescribed routinely, especially for long-term treatment of aggression and psychosis in patients with dementia.

Depression is very common in PWD and many patients are prescribed antidepressants (Bains, Birks, & Denning, 2002). Similar to antipsychotics, the treatment with antidepressants of patients with dementia is also very common in clinical practice and therefore one Cochrane Review has been discussed here even though it has not been included into the systematic review itself

because it did not fulfil the criteria. Bains, et al. (2002) found that even though antidepressants are commonly prescribed there was only weak support for this practice. The authors drew this conclusion, however, from a very small number of studies with small sample sizes, evaluating drugs which are not routinely prescribed. Bains, et al. noted that this does not mean that antidepressants are ineffective, but rather that there is not much evidence to support their efficacy.

The Cochrane Collaboration reviewed the efficacy of aspirin in patients with VD in 2008. Rands and colleagues (2000) could not identify any eligible study to be included in their review and therefore had to conclude that there is no good evidence to support the efficacy of aspirin in treating patients with VD.

Several other reviews were conducted by the Cochrane Collaboration evaluating a range of different pharmacological interventions. Most reviews found no evidence for the benefit of the drug reviewed (Birks & Flicker, 2000; Hudson & Tabet, 2003) or only insufficient evidence (Li, et al., 2008) on which to base a conclusion.

Only the calcium channel blocker nimodipine showed a short-term benefit for patients with dementia by improving their cognition and global impression compared to the placebo group (Lopez-Arrieta & Birks, 2002). Again, no data on QoL could be identified or were eligible for inclusion in these Cochrane Reviews even though there is agreement that QoL as an outcome measure would add to the findings (Hudson & Tabet, 2003).

There is also an apparent gap in pharmacological reviews or studies including caregiver outcomes as objectives.

2.3.3.3 Complementary therapies

A variety of complementary therapies have been described and evaluated in the literature. A Cochrane Review on Ginkgo biloba conducted by Birks and Evans (2007) noted that extracts of the leaves of the maidenhair tree, Ginkgo biloba, have long been used in China as a traditional medicine for various disorders of health including memory and concentration problems. The

authors found no available data on QoL and, even though the drug appeared to be safe in use with no side effects, there was not enough evidence of a consistent and convincing benefit of Ginkgo for PWDs. In contrast to these findings, a study conducted in Germany in a sample of almost 700 patients with mild to moderate dementia found that Ginkgo biloba resulted in a higher QoL of patients and their caregivers using a non-dementia specific QoL instrument (Heinen-Kammerer, et al., 2005).

The efficacy of Vitamin B 1 (thiamine) for people with AD has also been reviewed, but Rodriguez, et al. (2001) found insufficient data to be able to draw conclusions from this review.

The same applies to a Cochrane Review conducted by Thorgrimsen and colleagues (2003) on the efficacy of aroma therapy as an intervention for PWDs. Only one small trial was included in the review and, even though it showed results in favour of aromatherapy regarding neuropsychiatric symptoms, this was not enough data from which to draw conclusions.

2.3.3.4 Non-pharmacological supports and interventions

The author identified five original studies and one systematic review regarding a variety of non-pharmacological interventions and support for PWDs and their caregivers. The original studies suggested that:

- early diagnosis and intervention can improve patients' QoL (patient- and proxy rated);
- combined supports achieve better outcomes than single interventions (for example, day care alone), including behaviours, mood and patient QoL;
- occupational therapy can improve outcomes for both patients and caregivers, including caregiver depression and QoL;
- educational interventions targeting problem behaviours and patient mood can improve caregiver outcomes such as depression, burden and reactivity to difficult behaviours, as well as patients' behaviours and QoL (proxy rated).

The Cochrane review did not identify enough high quality trials from which to draw conclusions regarding the effects of reminiscence-therapy in dementia. Nevertheless, the authors of the Cochrane Review found some promising indications for the efficacy of reminiscence-therapy.

In conclusion, non-pharmacological interventions play an important role in dementia care not only for PWDs but also for caregivers. Optimal outcomes can be achieved through early diagnosis and intervention, through a combination of interventions such as education, occupational therapy, counselling and day care and by targeting PWDs and caregivers.

The following sections will outline specifically which non-pharmacological interventions have been reviewed regarding patients' and caregivers' QoL.

2.3.3.4.1 Interventions to promote health, well-being and cognitive functioning

A wide range of different interventions to improve cognitive and non-cognitive symptoms in dementia has been evaluated including exercise, behaviour management, reality orientation, cognitive stimulation, reminiscence-therapy and validation-therapy. Overall these approaches have been less studied than pharmacological interventions but, unlike pharmacological intervention, non-pharmacological intervention studies have often included caregiver outcomes in addition to patient variables. For a number of available interventions such as bright light therapy, music therapy, Snoezelen therapy/multi-sensory stimulation and environmental manipulation no level-1 or level-2 papers were identified.

Physical exercise and occupational therapy

The database searches identified one level-1 paper: Graff, et al. (2007) investigated the effects of community occupational therapy on QoL, mood and health status in PWDs and their caregivers. Occupational therapy aims at improving patients' ability to perform ADLs, promoting independence and participation in social activities, and reducing caregiver burden (Graff, et al., 2007). Administering the DQoL to patients with mild to moderate dementia and to the caregivers, the authors found that all overall outcome scores were statistically significantly better in the

intervention group than in the control group at 6- and 12-week follow-up. The intervention consisted of 10 1-hour sessions held over 5 weeks and focussed on patients and caregivers.

Dooley and Hinojosa (2004) also evaluated an occupational therapy intervention but in patients with mild to moderate AD (MMSE of 10 or more) and their caregivers in the USA. Using the BI and the Physical and Instrumental Self-Maintenance Scale, the authors found that there was a significant difference between treatment and control group in the levels of caregiver burden and in three patient QoL aspects: positive affect, activity frequency and self-care status.

A recent Cochrane Review found only insufficient evidence to base conclusions upon regarding the possible benefit of physical activity programmes for PWDs and their caregivers (Forbes, et al., 2008).

One RCT combined an exercise programme (30 minutes/day moderate to intense in-home exercise) for patients with a behavioural management component which taught caregivers to identify and modify patients' difficult behaviours and their own reaction to those behaviours (Teri, et al., 2003; Teri, et al., 2005). The intervention improved physical health and depression in patients with AD in the USA.

Behaviour management

Behaviour management aims at modifying problem behaviours by analysing the circumstances in which the behaviour occurs in order to identify important antecedents and consequences of the behaviour (Bartlett, et al., 2007). "Behavioural modification is then undertaken by changing these circumstances and/or teaching participants new behaviours" (Bartlett, et al., 2007).

The combined exercise and behavioural management programme which Teri, et al. (2003) used successfully in patients with AD and their family-caregivers (p. 81) was partly based on a previously established treatment to reduce behavioural problems in AD. In a sample of 72 patient caregiver dyads with patients being diagnosed with AD and minor or major depressive disorder, the authors found the two behavioural non-pharmacological treatments to result in significant

improvements of depressive symptoms and diagnosis in both treatment groups as compared to two control groups (Teri, Logsdon, Uomoto, & McCurry, 1997). Treatment effects were maintained at 6-month follow-up and effects were also observed in caregivers (n = 32) of both treatment groups who improved their own depressive symptoms while caregivers of the control groups did not.

In a study conducted in the USA, Gitlin, et al. (2008) aimed to test whether the Tailored Activity Program reduces dementia-related neuropsychiatric and behavioural symptoms, promotes activity engagement, and enhances caregiver well-being. The eight-session occupational therapy intervention involved neuropsychological and functional testing, selection, and customization of activities to match capabilities identified in testing, and instruction to caregivers in use of activities. At 4 months, compared to controls, intervention caregivers (n = 27) reported reduced frequency of problem behaviours, and specifically for shadowing and repetitive questioning, and greater activity engagement including the ability to keep busy. Caregiver benefits included fewer hours doing things and being on duty, greater mastery, self-efficacy, and skill enhancement. Depressed (and non-depressed) caregivers effectively engaged in and benefited from the intervention. The intervention showed no impact on patients' QOL-AD scores, depression scores (CSDD) or caregivers' subjective burden (Zarit BI). The authors concluded that tailoring activities to the capabilities of dementia patients and training families in activity use resulted in clinically relevant benefits for patients and caregivers. Treatment minimised trigger behaviours for nursing home placement and reduced objective caregiver burden.

The author also identified five systematic reviews focussing on interventions for difficult behaviours in dementia. All five reviews had to be excluded from the review, mainly for two reasons:

First, four (Cohen-Mansfield, 2004; Finnema, Droes, Ribbe, & Van Tilburg, 2000; Opie, Rosewarne, & O'Connor, 1999; Verkaik, van Weert, & Francke, 2005) of the five reviews did not include QoL as

an outcome measure into their search strategies. Only a review of psychosocial interventions for people with mild dementia searched systematically for studies with, amongst others, QoL as an outcome measure (Bates, Boote, & Beverley, 2004). The authors did not identify any study fulfilling this criterion.

Second, almost all studies included in any of the five reviews were conducted in nursing or residential care facilities. The papers therefore did not meet the requirement of contributing data to this review and study which focuses on PWDs residing in the community and being cared for by their families or friends.

This gap in knowledge was already noted 2 years ago by Bartlett, et al. (2007): "little is known about the effect of the interventions in the home situation. This is an area that requires further investigation" (p. 174). Considering the fact that only one level-1 and one level-2 paper were included for this current review of interventions for PWDs who experience behavioural symptoms and live in the community and their caregivers, it has to be concluded that Bartlett's notion still holds 2 years later and is also true for QoL as an outcome measure of those interventions.

Reality orientation therapy

Reality orientation therapy is based on the idea that impairment in orientating information (day, date, time and use of names) prevents PWDs from functioning well and that reminders can improve functioning (Livingston, et al., 2005).

Onder, et al. (2005) conducted a randomised controlled trial in Italy to evaluate the efficacy of reality orientation therapy combined with ChEIs in patients with mild to moderate AD. The treatment group showed a slight improvement in cognition compared to a decline in the control group. No significant effect was observed for behavioural and functional outcomes as well as for any of the caregiver outcomes (burden, depression, anxiety, QoL). The authors concluded that reality orientation enhances the positive effects of donepezil on cognition in AD.

Cognitive training and stimulation

The Cochrane Collaboration conducted one systematic review which evaluated the effectiveness and impact of cognitive training and cognitive rehabilitation interventions aimed at improving memory and other aspects of cognitive functioning for people with mild AD or VD (Clare & Woods, 2003). The review included QoL as an outcome measure but no study was identified which could have been included with this variable. The authors found that there were no significant positive or negative effects of cognitive training observed in the reviewed randomised controlled trials. No study of cognitive training was identified. The authors concluded that there was no evidence for the efficacy of cognitive training and insufficient evidence to evaluate cognitive rehabilitation in improving cognitive function for people with mild AD or VD.

Cognitive stimulation therapy was derived from reality orientation therapy and uses information processing rather than factual knowledge to address problem in functioning in patients with dementia (Livingston, et al., 2005).

A systematic review of psychosocial approaches to manage neuropsychiatric symptoms was conducted by Livingston, et al. (2005). The review showed that cognitive stimulation therapy resulted in three of four randomised controlled trials in some positive outcomes like improvement of problematic behaviours and decrease in depression. One of the three trials showed some improvement in patients' QoL. This latter trial, conducted by Spector, et al. (2003) in the UK, had also been identified by the author of this current review. Even though the authors had used the QOL-AD as an assessment tool, the study was still excluded from this review because the majority of participants were nursing home residents (n = 172) and only 29 participants were day care clients. Also, the results were not reported separately for both groups (mixed setting).

Reminiscence-therapy

Reminiscence-therapy stimulates memories and enables people to share and value their past experiences with the aid of tangible hints such as photographs and newspaper articles (Livingston, et al., 2005).

One of the very few Cochrane Reviews which identified and included a study (Thorgrimsen, et al., 2002) with QoL as an outcome measure, was conducted by Woods, et al. (2005). Unfortunately, the number of participants in this and the other trials reviewed was too small for the authors to draw conclusions from even though Woods, et al. found a number of promising indications for the efficacy of reminiscence-therapy in dementia. The small number of patients ($n = 11$) was also the reason the study conducted by Thorgrimsen, et al. could not be included in this review even though it reported patients QOL-AD scores. Nevertheless, the systematic review was graded a level-1 paper.

Validation-therapy

Validation-therapy is intended to give an opportunity to resolve unfinished conflicts by encouraging and validating expressions of feelings (Livingston, et al., 2005).

Again, the Cochrane Collaboration conducted a systematic review evaluating the effectiveness of validation-therapy for PWDs (Neal & Barton Wright, 2003). The authors identified three studies which met the inclusion criteria. The results showed no statistically significant effect for measures of cognition or ADLs although one study measured a positive impact on depression at 12 months and another study measured a positive impact on behaviour at 6 weeks. The authors concluded that there was not enough evidence to support the efficacy of validation-therapy for PWD.

2.3.3.4.2 Education

One study was identified which fulfilled the criteria for a level-1 paper. Teri, McCurry, Logsdon and Gibbons (2005) successfully trained community consultants in the USA to teach caregivers “a systematic behavioral approach for reducing mood and behavior problems in persons with

Alzheimer's disease" (p. 802). Compared to the control group, caregivers who received the training showed significantly greater reductions in most outcomes: depression, burden and reactivity to difficult behaviours. Patients' QOL-AD scores were rated higher by caregivers in the intervention group and patients' frequency and severity of difficult behaviours was also reduced in the intervention group. All results were maintained at 6-month follow-up.

Four studies were graded level-2 papers. All four studies showed improvements for at least some if not most outcomes. Chien and Lee (2008) found that a dementia care management programme (a 6-month education and support group) in Hong Kong resulted in statistically significant differences between intervention and control group regarding caregivers' QoL and burden and patients' symptom severity and frequency.

Similar to the dementia care management programme, Perren, Schmid and Wettstein (2006) also used a psycho-educational intervention to impact caregivers' well-being. This group intervention, conducted in Switzerland,, consisting of eight weekly sessions, aimed at improving caregivers' knowledge about dementia, improving caregivers' self-care, optimising the patient-caregiver relationship dynamics and increasing caregivers' service utilisation by raising their social competence. The authors found at 1- and 2-year follow-ups that, even though increase in difficult behaviours and cognitive and functional impairment were associated with decreased caregiver well-being, this association was less strong for caregivers in the intervention group.

In the USA, Burns, Nichols, Martindale-Adams, Graney and Lummus (2003) used educational material for one group of caregivers who only received a patient behaviour management component and for another group who received in addition a stress-coping component. The authors found that caregivers overall were less bothered by patients problem behaviours. Caregivers receiving the single component intervention had worse well-being and a trend toward increased risk for depression compared to caregivers receiving both intervention components.

A pre-post interventional study, conducted by Kuzu, et al. (2005) in Turkey, showed that an educational programme targeting problems which are likely to be experienced by caregivers of persons with AD reduced caregiver outcomes, including disturbed sleep, trauma risk and anxiety. The programme also resulted in decreased caregiver depression scores and increased caregiver HRQoL scores.

2.3.3.4.3 Counselling

All publications regarding the following three studies were graded level-2. In two of the included studies researchers, reported a beneficial effect of the interventions on caregivers' depressive symptoms.

Roth, Mittelman, Clay, Madan and Haley (2005) obtained data from more than 300 caregivers in the USA who had provided care for at least 1 year. The intervention consisted of three components: two individual counselling sessions, caregivers' participation in a support group and ad hoc telephone counselling. The control group caregivers received information about resources and advice and referral as well as counselling upon request. The authors found that the intervention improved caregivers' satisfaction with social support which was only modestly correlated with the increased amount of support received and the increased number of support persons involved (this did not include the counsellor provided by the study). It was concluded that some aspects of satisfaction with social support are independent of objective measures of support. The authors also found that improved perceived support decreased caregivers' stress appraisal and depression scores.

These latter findings were published in three further articles by this research group: Mittelman, Roth, Haley and Zarit (2004). The authors focused on the effect counselling and support had on caregivers' appraisal of patient behaviours. The authors found that the intervention had no impact on the frequency of problematic behaviours, but it reduced the negative reactions that caregivers had against these behaviours.

In the second and third article, the authors focussed more on the significant reduction of depressive symptoms in caregivers, an effect which was sustained for more than 3 years after baseline across different patient severity levels and after nursing home placement or death of the PWD (Mittelman, Brodaty, Wallen, & Burns, 2008; Mittelman, Roth, Coon, et al., 2004). By analysing a sub-sample of the same study of 158 spouse caregivers in the USA, UK and Australia, Mittelman, Brodaty, et al. (2008) evaluated the effectiveness of ChEIs for patients with AD in combination with counselling for caregivers of these patients. Caregivers received five sessions of individual and family counselling within 3 months of enrolment into the study and ad hoc telephone counselling upon request for the entire study duration of 24 months. The authors found that depressive scores in the intervention group decreased over time while they increased in the control group, where patients also had taken ChEIs but caregivers had not received counselling. Mittelman, Brodaty, et al. concluded that counselling can reduce caregivers' depressive symptoms when patients are taking donepezil.

In a fourth publication, Mittelman, Haley, Clay and Roth (2006) showed that the same counselling and support intervention for caregivers, as described before, also reduced the rate of nursing home placements of persons with AD.

A study conducted by Charlesworth, et al. (2008) in the UK investigated the effectiveness of a befriending programme. The programme aimed at enhancing psychological well-being and QoL for caregivers (n = 236) of PWDs. Befriending volunteers provided emotional support for their matched caregivers through companionship, conversation and listening. The researchers excluded advice giving and practical caring tasks from the role of the befriending volunteers. The main outcome was the caregivers' mood (depression); secondary outcomes included caregivers' HRQoL, anxiety, positive affect, loneliness and perceived social support. The intervention was found to have no positive impact on any of the outcome measures and the authors concluded that a befriending scheme is not effective in improving caregivers' well-being.

2.3.3.4.4 Respite care

Respite care is an umbrella term covering a wide range of services that provides caregivers temporary periods of rest away from the PWD, including day care, in-home respite care/ sitter-service or assisted vacations. The only level-1 paper identified for respite care was published by Edelman, et al. (2004). Here, the authors did not report on the impact of day care on clients' QoL. Instead the authors compared five different dementia-specific QoL measures in relation to patients' impairment of daily functioning in the USA. Therefore this study has also been discussed earlier within this review (2.3.1.6). Edelman, et al. applied the following disease-specific QoL scales:

1. the DQoL (Brod, et al., 1999);
2. the Quality of Life-AD/R (Residents) (Edelman & Fulton, 2000), an adaptation from the QOL-AD (Logsdon, et al., 2002)
3. the Quality of Life-AD/S (Staff) (Edelman & Fulton, 2000), an adaptation from the QOL-AD (Logsdon, et al., 2002);
4. the ADRQOL (Rabins, et al., 1999);
5. Dementia Care Mapping (DCM) (Bradford Dementia Group, 1997).

Ratings from the first two scales were based on day care client interviews; the third and fourth scale were administered to staff of the three adult day care centres involved; DCM is a detailed observational method for up to eight persons at 5-minute intervals of up to 6 hours. In addition, cognitive impairment (MMSE), functioning (Katz', et al. ADL scale) and depression (CSDD) were also assessed. The data analysis showed that clients (n = 54) rated their QoL on average higher than did staff. Client ratings did not correlate with any of the additional measures but there was a high correlation between the self rated DQoL and the Quality of Life-AD/R scores. Staff's proxy ratings of clients' QoL were all strongly correlated with each other and also with most of the additional measures. The authors concluded that functional impairment is associated with

diminished QoL of day care clients from staff members' point of view and as indicated by observational measures.

The following six articles have all been graded as level-2 papers. The systematic review conducted by Lee and Cameron (2004) included three trials based on which the authors found no evidence for the efficacy of respite care for PWDs or for their caregivers. Lee and Cameron (2004) warned that "these results should be treated with caution, however, as they might reflect the lack of high quality research in this area rather than an actual lack of benefit" (pp. 1, 2).

These findings are supported by results from a study conducted by Lawton, Brody and Saperstein (1989) in the USA. Lawton, et al. (1989) found different forms of respite to be ineffective for caregivers' burden, well-being and depressive symptoms. Despite these results the satisfaction level with respite care programmes was very high.

Another study, conducted in Australia by Wells, Jorm, Jordan and Lefroy (1990), also supports the findings reported by Lee and Cameron (2004). The authors found that the high levels of caregivers' psychological symptoms were not reduced by using day care (Wells, et al., 1990). After 3 months of continuous day care utilisation, however, caregivers reported more often having time to themselves.

As shown by Coen, et al. (2002) in a study conducted in Ireland, having time to themselves can significantly impact caregivers' QoL. Coen et al. (2002) identified two factors that differed between a low and a high burden group of caregivers. One of these factors was 'finances'. The other factor was 'time for self'. The authors concluded that the need for more time for self had a significant and direct impact on caregiver QoL. They argued that caregivers' QoL could be improved through greater availability and better promotion of formal respite services.

Mavall and Thorslund (2007) also showed the positive impact of dementia day care on some caregiver outcomes in Sweden. After 4 months of starting day care, caregivers of patients who

continuously attended the programme scored significantly lower for worries, overload and role captivity compared to caregivers of patients who had dropped out of the programme.

2.3.3.4.5 Multi-component interventions

The systematic search for literature identified two level-1 papers which investigated the effects of combined supports for PWDs and their caregivers. The first study was conducted in the Netherlands by Droes, et al. (2004). The authors explained the study design:

Dementia patients who participated in the integrated Meeting Centres Support Programme, that also supported the carers, in eight community centres outside the Amsterdam region (the experimental group), were compared on a number of behavioural aspects and mood to visitors with dementia of three nontegrated (*sic.*) regular psychogeriatric day care centres of three nursing homes in the Amsterdam region (the control group). (p. 674)

Droes, et al. (2004) found that after 7 months the intervention programme compared to regular day care showed a positive effect in patients on behavioural problems, depression and self-esteem. Self-esteem was measured as one of five sub-items on the DQoL. No correlation was found for any of the other DQoL items. The authors concluded that the combined intervention is more effective than regular day care in regard to patients' difficult behaviours, depression and self-esteem.

The second paper investigated the Croydon Memory Service Model which has been developed in the UK in order to identify PWDs and to engage with PWDs and their caregivers early (Banerjee, et al., 2007). In addition, the Croydon Memory Service Model also aims at providing a comprehensive assessment, as well as a diagnostic and treatment service for PWDs and their caregivers. The core idea of the model is generic team working so that the initial assessment can be carried out by any health professional irrespective of their clinical background. The diagnosis and treatment plan are the result of a multidisciplinary team approach. The authors found that this model increased the

number of new cases identified in Croydon by 63%, from 255 to 416 people diagnosed with dementia per year. Using the self rated DEMQOL and caregiver rated DEMQOL-Proxy as well as the NPI, the authors observed at 6-month follow-up that those referred to the services had decreased behavioural disturbances and increased QoL compared to baseline. Banerjee, et al. (2007) concluded that specific services for early dementia, which deliver diagnosis and care, can be established successfully, and those services can increase the numbers of people with early dementia identified and provided with care. The authors further concluded that “those receiving such services appear to improve in terms of quality of life and behavioural and psychological symptoms of dementia” (p. 787).

A number of level-2 studies were identified which evaluated multi-component interventions and found them all to have positive impact on patient and/or caregiver outcomes. Brodaty and Low (2004) found in Australia that the Making Memories programme, consisting of education sessions, individual counselling, occupational therapy, diversional therapy to enhance leisure activities and ongoing support groups, decreased psychological distress in PWDs. It also had a short-term beneficial effect on caregivers’ reaction to patients’ difficult behaviours.

Another study, conducted by Belle, et al. (2006) in the USA, measured the following QoL outcomes: caregiver depression, burden, self-care and social support, and patients’ problem behaviours and institutionalisation. The intervention consisted of 12 in-home and telephone sessions over 6 months time comprising mainly of different educational strategies and techniques as well as reinforcement of available supports. Caregivers in the control group received two brief phone calls during the intervention period and an invitation for a dementia workshop after the intervention period. Caregivers of different ethnicities improved on all QoL outcomes in both groups but caregivers in the intervention group improved more than caregivers in the control group. Interestingly, no overall statistically significant impact was found for African-American caregivers but only for African-American spouses who improved slightly less than Hispanic or Caucasian caregivers. At 6-month follow-up no impact was found regarding institutionalisation.

In a third study, conducted by Vickrey, et al. (2006) in the USA, the authors also found positive effects of a multi-component dementia guideline-based disease management programme on quality of care and patient outcomes. By assigning a care manager to each patient-caregiver dyad, providing clients with an in-home assessment, using the care manager to organise collaboration between the clients and different care facilitator as well as providing ongoing support and re-assessments every 6 months the authors observed an improvement in most care outcomes: patients' HRQoL, as measured using the EQ-5D, "overall quality of patient care, caregiving quality, social support and level of unmet caregiving assistance need were better for participants in the intervention group than for those in the usual care group ($p < .05$ for all)" (p. 713). Caregivers' HRQoL was not influenced by the intervention.

Only one study, conducted by Mohide, et al. (1990) in Canada, found that a multi-component intervention (consisting of education, support group, in-home respite and caregiver focused health care) did not improve patient and caregiver outcomes as strongly as similar interventions in other studies. However, despite the consistent high depression and anxiety scores, using the "Caregiver Quality of Life Instrument - CQLI (Mohide, Torrance, Streiner, Pringle, & Gilbert, 1988), Mohide, et al. (1990) did find a 20% difference from the baseline CQLI scores in the intervention group. The number of participants at follow-up was too small ($n = 42$) to show statistical significance, but the authors considered the 20% difference to be a clinically significant result. The authors also found that "the experimental group (...) experienced a slightly longer mean time to institutionalization (*sic.*), found the caregiver role less problematic, and had greater satisfaction with nursing care than control group" (p. 446).

2.3.4 Economic impact of dementia

Dementia poses not only an enormous health but also an economic burden on society. This burden will increase dramatically during the next 20 years due to the changing structure of society (Logsdon, et al., 2002). The number of people with dementia will increase in the Asia Pacific region from 13.7 million persons in 2005 to 64.6 million by 2050 (Access Economics, 2006). In March 2009 the US Alzheimer's Association published the most recent numbers regarding dementia in the USA (Alzheimer's Association, 2009a). The organisation estimated that there are currently 5.3 million people with AD living in the USA, being cared for (aside from professional caregivers) by 9.9 million unpaid caregivers, costing a total of US \$148 billion every year.

Considering the worldwide societal financial burden of dementia and the fact that the main focus in dementia care has become to promote well-being and maintain an optimal QoL (Ettema, et al., 2005a), QoL as an outcome measure is not only becoming increasingly important in clinical assessments but also in economic evaluations. According to an economic impact report issued by Alzheimers New Zealand in 2008, currently there are almost 41,000 people with dementia in New Zealand and this number is estimated to nearly double by 2026 (Access Economics, 2008). This means that the prevalence rate will increase from 1.0% of the population in 2008 to 1.5% by 2026. The total costs of dementia in New Zealand were assessed as NZ \$712.9 million with 62.6% of costs financed through the Government and 30.6% financed privately (Access Economics, 2008). Based on residential care data, the authors performed a cost-benefit analysis (CBA). Findings revealed that a delay of admission to residential care by 3 months would result in a 23% reduction in the number of days of residential care provided to PWDs and a saving of NZ \$62.3 million. The total costs for informal caregiving time to keep the PWD at home as long as possible, plus other community care costs (including respite care) added to a total of NZ \$30.5 million. It was therefore calculated that delaying institutionalisation by 3 months would result in a net-benefit of NZ \$31.8 million (Access Economics, 2008). The authors further explained that “this equates into a benefit:cost [*sic*] ratio of 2.04, which means that each marginal dollar currently invested in

community care services to delay institutionalization (*sic.*) returns around NZ \$2.04 in reduced residential care costs” (p. 72). The report relied heavily on estimates since “no epidemiological studies of dementia incidence or prevalence in the New Zealand population or in specific ethnic groups” could be identified by the researchers (p. 8). The authors also explained that the report had been limited by the lack of comprehensive data of either of the two main types for estimating direct health system costs: the ‘top-down’ data which “can be derived from central data collection agencies” or the ‘bottom-up’ approach which estimates costs using “surveys, diaries or other cross-sectional or data-gathering tools” (p. 15). For example, it was not possible for the researchers to find an existing comprehensive bottom-up study of dementia-related costs in New Zealand.

Aside from medical costs and formal and informal care costs, comorbidities also contribute significantly to costs in dementia. Kuo, Zhao, Weir, Kramer and Ash (2008) analysed data from a sample of more than 25,000 AD patients from an US Medicare health insurance database which had made at least one claim for one of the anti-dementia drugs. The authors reported that patients with AD had more comorbid conditions and caused 34% higher annual costs than control group participants. Costs still remained higher for AD patients after controlling for a non-AD related illness burden with outpatient pharmacy being the largest cost item. It has been shown that there are possibilities to save dementia related costs.

This section reviews what is known about QoL in dementia regarding direct costs (2.3.4.1) (p. 96) and indirect costs (2.3.4.3) (p. 105), as well as the financial burden (2.3.4.4) (p. 107). The author could not identify any level-1 paper regarding economic aspects of dementia and QoL and the following section is therefore based on 14 level-2 papers which are all listed in ‘Appendix B: Included papers level-2’ (p. 377).

2.3.4.1 Direct medical costs

A review regarding the expense of dementia and dementia care emphasised that the costs differ considerably in the literature because the number of cost items included in economic studies

varies, resulting in a wide range of costs (Wimo, et al., 1997). Wimo, et al. (1997) revealed that the evaluation of informal care costs is particularly complicated but at the same time important, since informal care accounts for a large part of the total costs in dementia care.

Studies have indicated that relatively small delays in the onset and progression of dementia could substantially reduce disease-related costs (Access Economics, 2006; Brookmeyer, et al., 1998). Many psychosocial and pharmacological/diagnostic interventions have been shown to be cost-effective (Brodaty, et al., 2003; Clegg, et al., 2002). Nevertheless, most studies focus on medications. Economic studies have shown that these pharmacological interventions may have three important impacts: delay the institutionalisation of a person with dementia, reducing the number of hours of informal care giving, and improving the QoL of people with dementia and their caregivers (Access Economics, 2006).

The author could not identify any level-1 paper regarding direct costs and QoL in dementia. In summary, the review of eight level-2 papers suggested the following:

- Community occupational therapy can not only be effective regarding patients' and caregivers' QoL, mood and health status but can also be cost-effective.
- Residential care, home help and unpaid caregiver time are major cost factors in mild to moderate AD.
- Patients with LBD utilise more resources, and give rise to higher costs of care than AD patients.
- In Sweden, costs are lower and the gain of QALYs is greater for PWDs living in specialised dementia groups which offer a transition between home and permanent care settings as compared to PWDs living at home or in residential care.
- Caregiver support programmes providing counselling, support and education can improve caregiver QoL at costs per QALYs gained which compare favourably with other health care interventions.

- Higher levels of caregiver stress can cause an increase in the use of medical services.
- Medical and non-medical costs of PWDs living at home, not including costs of informal caregiving time, increase with the severity of functional as well as cognitive impairment.
- Costs increase more with the severity of patients' functional disability than with cognitive impairment.

The only study which would have met the criteria for a level-1 paper was conducted by Graff, et al. (2008; Graff, et al., 2007) in the Netherlands. The authors not only investigated the effects but the cost effectiveness of community occupational therapy on QoL, mood and health status in PWDs and their caregivers. The results of this study were published in two different articles: the first covered the positive impact of occupational therapy on all outcome measures (Graff, et al., 2007); the second covered the cost effectiveness of the intervention (Graff, et al., 2008). For the economic aspect of the study the authors chose to define patients' process- and performance skills of ADLs, as well as caregivers' competence and not the DQoL scores as the main outcomes against which cost effectiveness was calculated. Therefore the cost effectiveness study within the intervention study and the relevant article were graded as a level-2 paper. Nevertheless, the intervention proved not only effective (Graff, et al., 2007) but also cost effective (Graff, et al., 2008).

Birks and Harvey (2006) found in their Cochrane Review of Donepezil that there was little evidence of a difference in the cost of health resource utilisation between the treatment and the placebo groups. The authors noted that the two studies from which their conclusions were drawn were conducted in several countries, which made interpretation difficult. Nevertheless, the major components of costs in both studies were due to residential care, home help and unpaid caregiver time in a sample of patients with mild to moderate AD. The authors also found that the benefits of a 10mg/day dose were only marginally better than the 5mg/day dose. Taking into consideration that the higher dose caused more side effects in patients and that it is associated with higher costs

the authors concluded that the lower dose of 5mg/day may be the preferable choice for health care practitioners.

Bostrom, Jönsson, Minthon and Londos (2007) found that patients with LBD from Sweden, Finland and Norway utilise more resources, and cause higher costs of care than AD patients (€37,000 versus €18,200 per year.). The authors also observed a significant correlation between LBD patients' dependency in IADLs and patients' resource use.

To relate costs to QoL or aspects of well-being a cost-utility analysis (CUA) can be conducted which compares two or more alternative treatments or interventions. Non-pharmacological economic studies in the field of dementia often use the concept of a quality-adjusted-life-year (QALY). Drummond, et al. (2005) described the use of the QALY concept as "one of the key features of conventional CUA" (p. 173). The authors continued by giving detail about the concept of QALYs: "QALY as a measure of health outcome is that it can simultaneously capture gains from reduced morbidity (quality gains) and reduced mortality (quantity gains), and combine these into a single measure" (p. 173). Wimo, et al (1995) explained that QALYs are calculated "by assigning different utility values to different states of health" (p. 50) The utility scale ranges from 0 (dead) to 1 (perfect health). The concept allows evaluating the difference in costs as well as the difference in outcome if an alternative treatment was chosen. The outcome measure is expressed in cost per QALY gained. The authors also pointed out that "in dementia no matter what is done, progression causes an increase in costs and a deterioration in utility" and that a CUA in dementia therefore, cannot evaluate an intervention aiming at absolute improvement but aiming at the lowest increase in costs and the least deterioration in health (p. 62).

A CUA of group living in dementia care was conducted in Sweden (Wimo, et al., 1995). As the authors explained, group living is "an intermediate level of care between home and institution" (p. 49). Wimo, et al. (1995) found that the costs were lower and the gain of QALYs was greater for PWDs living in specialised groups as compared to PWDs living at home or in residential care. It was

concluded that the costs per QALY was < 0 . Nevertheless, the authors did indicate some methodological issues.

Another CUA was conducted by Drummond, et al. (1991) in Canada, who evaluated the cost-efficiency of a caregiver support programme as compared to the usual care. The intervention programme consisted of nurses' home-visits, GP consultations, and a caregiver support group providing counselling, support and education regarding caregivers' own health and patients' illness. Using a non-dementia specific questionnaire the authors assessed caregivers' QoL and found that QoL increased in the intervention group but decreased in the usual care group. The difference of 20% between both groups did not reach statistical significance but was considered clinically meaningful by Drummond and colleagues. The authors also calculated that an improvement of caregivers' QoL would imply costs of Canadian \$20,000 per QALYs gained "which compared favourably with other health care interventions" (M. Drummond, et al., 1991).

Health care systems around the world also experience an increasing financial burden because dementia not only causes an increase of patient related costs but also of caregiver related costs. A recent study conducted in the USA by Son, et al. (2007) examined the impact of caregiver stress factors on different caregiver outcomes, including direct medical costs. The authors found that caregivers of persons at different stages of dementia with behavioural problems, living in the community, rated their own health lower, had more negative health behaviours and had higher expenditures for health service use. Son, et al. concluded that higher level of caregiver stress can cause an increase in medical service use.

Caregivers are crucial for enabling PWDs to live in the community as long as possible. Without a caregiver, or when a caregiver is stressed, the likelihood of nursing home admission rises sharply (Brodaty, et al., 1993). An estimated 2.3 million Australians (about 20% of the total population) care for family members or friends with a disability, chronic condition or who are frail aged. This workforce saves the Australian economy an estimated A \$16 billion annually and is the major

provider of community care (Access Economics, 2003). These numbers are based on the replacement costs approach. Based on this approach the value of informal care of people with dementia was over A \$1.7 billion in Australia in 2002 – about one-third of the overall costs. Part of the value of informal care is compensated through governmental programmes, but 80% of the value of informal care is provided without compensation (Access Economics, 2003). For the 15 Asia Pacific region ADI members the proportion of the estimated informal costs (US \$26.8 billion) out of the total costs (US \$60.4 billion) is even higher than in Australia. In New Zealand, 48% of PWD live at home. Using the cost-replacement method it was estimated that the value of informal care was NZ \$402.1 million in 2008 (Access Economics, 2008).

Two of level-2 papers focused on costs of informal caregiving time in relation to QoL and patient dependence. Andrieu, et al. (2007) examined the impact of PWDs impaired functioning (ADLs/IADLs) on caregivers' QoL, health, depressive symptoms and sense of competence. The authors analysed a sub-sample of a 1 year prospective cohort study (which investigated the socioeconomic consequences of dementia in Belgium²⁸), consisting of 145 PWDs and their caregivers, living in the community. The findings revealed that patients' level of dependency was significantly correlated to caregivers' satisfaction with caregiving, subjective burden, QoL and depression. Medical and non-medical costs of PWDs living at home, not including costs of informal caregiving time, increased with the severity of functional as well as cognitive impairment. Costs increased more (overall by 160%) with the severity of functional disability than with cognitive impairment.

The second paper with focus on patient dependency and direct costs was published by Zhu, et al. (2008). Data were obtained from 172 AD (or probable AD) patients in the USA who were at baseline all at early stages of the illness. Patients were followed for up to 6 years and data from annual assessments on health care utilisation and costs were only included in the study if

²⁸ See also Kurz, et al. (2003).

patients lived at home at the time of the assessment. The findings were similar to the results obtained by Andrieu, et al. (2007): Both patients' increased dependency on their caregivers for support with ADLs and IADLs as well as patients' decreased functional capacity were associated with higher costs of care and caregiving time.

2.3.4.2 Direct non-medical costs (informal caregiving hours)

The author could not identify any level-1 paper regarding informal supports and QoL in dementia and the following section is therefore based on eight level-2 papers which are all listed in 'Appendix B: Included papers level-2' (p. 377).

In summary, the biggest component of informal support which PWDs receive is caregiving time provided by their primary family-caregivers such as spouses, children or friends. Around the world governments and health systems depend on relatives and friends to care for PWDs. However, the often extensive caregiving hours have significant negative effects on caregivers' physical and psychological health, including high levels of psychological distress and increased risk for depression. More burdened caregivers appraise their level of informal social support as less adequate than caregivers who feel less burdened. But caregiver role-stress also has a clear negative impact on patients' QoL outcomes such as patients' behaviours during social contacts. Nevertheless, it has been shown that the need for informal caregiving and therefore the time spent on informal care can be reduced. Day care can not only reduce the frequency of neuropsychiatric and behavioural symptoms in PWDs but also the time caregivers spent on symptoms. Also, religious well-being and satisfaction with support from friends from within the religious community were found to be strong predictors of caregiver QoL outcomes.

In detail, the following observations were made:

Wimo, von Strauss, Nordberg, Sassi and Johansson (2002) evaluated the time spent on informal and formal care giving for PWDs in Sweden. The authors reported that family-caregivers are

estimated to spend about 8.5 more times providing informal care to the patients than receiving formal care through services.

An Irish survey found that caregivers spent an average of just under 12 hours of specified care each day to PWDs (O'Shea, 2003). The same survey also showed that informal caregiving was associated with high a level of psychological distress which was observed in 73% of participants. O'Shea (2003) explained that the high caregiver distress might have been partly caused by the fact that these caregivers spent considerably more time caring than they would have wished - 11.6 hours instead of 8 hours per day.

Similar to O'Shea (2003), other studies also found a clear negative impact of extensive caregiving hours on caregivers' physical and psychological health. Markowitz and colleagues (2003) found in 2000 caregivers of AD patients in the USA that increased hours of caregiving were associated with poorer caregiver mental functioning and were also modestly associated with lower caregiver physical health scores (SF-12). The authors considered that mental health might have been particularly affected because long hours of caregiving may have diminished the time left for activities that could have sustained caregiver mental well-being. Markowitz, et al. also pointed out that treatment with ChEIs had been shown to reduce the number of hours of caregiving suggesting the possibility that a reduction in caregiving time may improve caregivers' HRQoL.

Covinsky, et al. (2003) found in the USA that spending more time with caregiving increased the risk for caregivers to be classified as depressed. Between 32.4 and 41.8 % of caregivers spending between 40 and 168 hours of care per week were depressed as compared to 15.3 % spending less than 40 hours per week caregiving.

It seems from a study conducted by Gaugler, et al. (2003) in the USA, that the need for informal caregiving and therefore the time spent on informal care can be reduced. The authors investigated the effects of day care on caregiving hours and care demands in a large sample of 400 caregivers. The authors found that clients who used a day care service for 3 months reported not only greater

decreases in the frequency of difficult behaviours but also in the time they spent on behavioural problems of the PWDs compared to caregivers who did not use day care. The authors discussed as a possible explanation for these findings that day care programmes in their study (such as art and music therapy or group exercise) did indeed reduce the frequency of negative behaviours. Another explanation might be that the stimulation offered in many day care programmes improved patients overall mood leading to less frequent problem behaviours. The authors continued by suggesting that this latter explanation also would fit with the fact that ADL and IADL hours did not decrease in the study since interventions such as art therapy could possibly have a positive impact on patients' mood but not on patients' level of cognitive impairment.

It is important to note that the impact of informal care on QoL outcomes has not only been described in caregivers but also in patients. For example, Burgener and Twigg (2002) examined how caregiver factors measured at 12 months follow-up impacted the QoL of PWDs at 18 months follow-up. The authors found that caregiver role stress (negative attitudes towards patient) and the actual number of patients' social contacts (facilitated by caregivers during the previous week) predicted patients' social behaviour. Social behaviour in this study measured patients' behaviours during social contacts and contained items such as "initiates conversation with family" using the dementia-specific Functional Behavior Profile (FBP) (Baum, Edwards, & Morrow-Howell, 1993). The finding that caregiver factors significantly predicted patient outcomes 6 months later proved for Burgener, et al. (2002) the relevance of caregiver role stress and facilitation of social contacts for patients in the early to moderate stages of dementia.

Some studies have raised the question of how important family and friends are in supporting caregivers in their role. It seems that the level of burden and the quality of relationships are important factors determining the level of informal social support as perceived by caregivers. Coen, et al. (2002) analysed two Irish groups of caregivers: a high and a low burden group. Using the Social Support Appraisals (SS-A) Scale (Vaux, et al., 1986) caregivers were asked to agree or disagree with 23 statements concerning appraisal of social support from family and friends.

Caregivers in the higher burden group showed a trend to appraise their level of informal social support as less adequate than caregivers who felt less burdened.

Burgener (1999) analysed the role of support from and involvement with the religious community in predicting QoL of caregivers of AD patients. Using a variety of different generic QoL scales in a sample of 271 caregivers the author found that both religious well-being and satisfaction with support from friends within the religious community were the strongest predictors of caregivers' QoL and role-stress related outcomes. Interestingly, the actual number of friends was less important than the satisfaction with support from close friends within the religious community.

The lack of studies regarding QoL in dementia and informal care is apparent. Nevertheless, some conclusions can be drawn from studies which assessed informal care and QoL using non-dementia specific scales. Family and friends spend a considerably larger amount of time providing care for the PWD than receiving formal support. These caregiving hours have a significantly negative impact on caregivers' physical and psychological health which consequently also negatively impacts patients' QoL. Formal support such as day care for PWDs as well as informal support from caregivers' social and religious networks can improve patient and caregiver measures of QoL.

2.3.4.3 Indirect costs

There were two level-2 papers that assessed indirect costs of dementia care. Both articles also evaluated direct costs. Mixed results of both cost approaches are outlined in the following overview:

- The average annual direct costs in 2001 per AD patient in the Canary Islands, Spain, were estimated at €28,198 (US \$36,144).
- The average early retirement costs (that is, morbidity costs) per patient in the Canary Islands, in 2001 were calculated to be €628 (US \$805) per year
- The total costs (direct and indirect) for all AD patients in Spain were estimated at €10 billion (US \$13 billion) annually in 2001.

→ Costs, including indirect cost, increase with increasing dementia severity, increasing behavioural symptoms as well as increasing functional limitations.

→ In 2001, the total annual costs of informal care (direct costs) plus productivity costs (indirect costs) in the USA were estimated at US \$18,385 per patient, with a majority of costs deriving from caregivers' lost earnings (US \$10,709) and the costs of caregiving time.

In detail, Lopez-Bastida, et al. (2006) explained that there is no agreement on the best way to assess indirect costs such as morbidity costs:

For the estimation of indirect costs and their subsequent conversion into monetary units, in most of the studies of this type, the Human Capital approach was used. The Human Capital method transforms years of life into monetary units by using the average gross earning per worker. Although the Human Capital approach has often been criticized, it has been widely used because of its easy assessment and of the lack of existing alternative approaches (p. 2188).

Morbidity costs in dementia can include early retirement of patients due to their dementia. The only study which assessed, in addition to QoL, not only direct but also indirect costs was conducted by Lopez-Bastida (2006) in the Canary Islands, Spain, and graded as a level-2 publication since the non-dementia specific EQ-5D was used to assess patients' and caregivers' QoL. The authors found in a sample of 237 outpatients at different stages of AD that the average annual direct costs in 2001 per patient were €28,198 (US \$36,144). The categories contributing most to the total amount were drugs and informal care. The average early retirement costs per patient were €628 (US \$805) per year. Costs increased significantly with increasing dementia severity (CDR). Patients' QoL as rated by their caregivers significantly decreased with dementia severity but the authors found no relation between caregivers' own QoL and illness severity. Lopez-Bastida, et al. concluded that "direct health care costs of AD represented 2.4% of the total public health care expenditure in the Canary Islands" (p. 2186). The authors estimated the total costs (direct and indirect) for all AD patients in Spain at €10 billion (US \$13 billion) annually.

One additional level-2 study (Moore, Zhu, & Clipp, 2001) was included in this review even though it did not assess QoL, since the database searches produced only one article (Lopez-Bastida, et al., 2006). The study conducted by Moore, et al. (2001) in the USA examined the informal care costs (direct costs) as well as caregivers' productivity costs (indirect costs) in a sample of more than 2000 male veterans diagnosed with AD or VD. The authors estimated the total annual costs of informal care plus productivity costs at US \$18,385 per patient with a majority of costs deriving from caregivers' lost earnings (US \$10,709) and the costs of caregiving time. Similar to Lopez-Bastida, et al. (2006), Moore, et al. (2001) also found that the costs of care increase rapidly as the dementia worsens: "For dementia patients who do not have any ADL limitations, the total cost of informal care is estimated to be \$12,995. By the time the patients are entirely ADL disabled, total costs of informal care increases to \$27,836" (p. S226) in the USA in 1998. In addition to functional impairment, the authors also reported that the severity of patients' problematic behaviours caused a significant increase in care costs.

2.3.4.4 Perceived individual economic burden

Not many studies have dealt with what could be described as the individual economic burden as perceived by caregivers of PWDs. Often the most basic economic data, like participants' income, are missing or they are reported only in a descriptive way without detailed analysis. Nevertheless, four studies could be identified for this review, none of which, however, applied dementia-specific QoL questionnaires and were therefore graded level-2. In summary, the review of these four level-2 papers suggested the following outcomes:

- Caregivers who are highly burdened consider that their financial situation is one of the most important determinants of their QoL.
- Caregivers of persons with moderate to severe dementia are at much higher risk to become depressed if they have a low income.
- Caregivers' reactions to depressive and disruptive behaviours of PWDs may put them at risk for loss of economic resources.

→ In Ireland in 2003, 84 % of family-caregivers of PWDs wanted to be paid for their time spent caring.

Using the SEIQoL-DW which asked participants to nominate the five aspects of life that they considered to be the most important determinants of their QoL, Coen, et al. (2002) identified two factors that differed between a low and a high burden group of Irish caregivers. One of these factors was 'finances'. The authors concluded that adequate financial assistance was central to the effectiveness of a comprehensive support system.

Covinsky, et al. (2003) found in a large sample of more than 5000 patients with moderate to advanced dementia and their families in the USA that caregiver with less income were at much higher risk to become depressed than caregivers with higher income.

The only study to use a questionnaire directly dealing with economic burden was conducted by Robinson, Adkisson, & Weinrich (2001) in the USA. Using the Cost of Care Index (CCI) (Kosberg & Cairl, 1986), the authors discovered that caregiver reactions to patients' problematic behaviours (memory loss and depression) were associated with the economic subscale of the CCI. The authors concluded those caregivers' reactions to depressive and disruptive behaviours may put them at risk for loss of economic resources.

A study conducted amongst caregivers in Ireland showed that 84 % of family-caregivers of PWDs wanted to be paid for their time spent caring (O'Shea, 2003).

The lack of studies regarding QoL in dementia and all three cost aspects reviewed here is evident. In economic studies, QoL is often neglected as an outcome measure. If QoL is assessed it is measured in QALYs based on non-disease specific instruments. Partly this is due to methodological issues, like a lack of a validated dementia-specific assessment tool for caregiver QoL and the disagreement of definitions for QoL and economic terminology. Furthermore, the resources required for comprehensive economic analyses are often difficult to cover and might be an

explanation of why the majority of economic research in dementia has been conducted in the form of pharmacological cost-effectiveness studies.

From the economic studies included in this review, however, it can be concluded that dementia causes a significant societal and individual financial burden. Some of the major contributors of the overall costs are residential care and (mostly) unpaid informal care time. ChEIs, like donepezil, may be an effective and cost-effective treatment especially in mild to moderate AD. Certain forms of dementia, like LBD, are more cost intensive than others. Cost-efficient alternatives for residential care already exist. Combined supports for caregivers can improve caregivers' QoL, measured in QALYs, at a price that compares favourably to other options. Caregivers' decreased psychological health contributed to an increase in dementia related costs. Costs increase significantly with patients' deterioration of daily functioning and cognitive impairment. Indirect costs, such as lost earnings, are hardly ever estimated but contribute significantly to the overall costs of dementia. Income can be a predictor of caregiver depression and becomes more relevant the more burdened caregivers feel.

2.4 Conclusions

This review leads to a number of conclusions. First and foremost, QoL in dementia should be considered as a multidimensional concept which can be best understood if not only the PWD's QoL but also their caregivers' QoL is assessed.

A dementia-specific QoL assessment tool is to be preferred to a generic instrument. The same could be true for caregivers. Some efforts have already been made to develop dementia-specific QoL scales for caregivers.

This review clearly showed that **QoL in PWDs is predicted** by a variety of clinical and non-clinical measures:

1. PWDs' level of depression: at all stages, but particularly at moderate to severe stage;

2. PWDs' neuropsychiatric and behavioural symptoms: at all stages; at mild to moderate stage patient is reliable source in addition to proxy ratings;
3. PWDs' level of daily functioning: at all stages; at an early stage PWDs can judge how much the level of impaired IADLs impacts on their QoL; proxy ratings of ADLs and IADLs are reliable for data collection at all stages;
4. PWDs' general health status or comorbidities (only two level-1 studies);
5. Caregivers' burden (only one level-1 study).

Many studies used proxy ratings to measure patients' QoL and found that these **proxy ratings** were associated with:

1. Severity of dementia (only one level-1 study);
2. PWDs' neuropsychiatric and behavioural symptoms;
3. PWDs' level of daily functioning;
4. PWDs' general health status or comorbidities (only two level-1 studies);
5. Caregivers' QoL (only one level-1 study);
6. Caregivers' burden (only one level-1 study);
7. Caregivers' level of distress as a reaction to PWDs' neuropsychiatric and behavioural symptoms.

Since all these outcomes influence how caregivers rate patients' QoL these proxy ratings should be treated with caution and patients should have the opportunity to present their own perspective on QoL if possible.

The two studies using dementia-specific tools to assess the QoL of caregivers suggest that the following factors impact **caregivers' QoL**:

1. Pathology of dementia (worse QoL for caregivers of persons with LBD compared to AD);
2. PWDs' QoL (proxy rated);
3. PWDs' neuropsychiatric and behavioural symptoms;
4. Caregivers' gender (worse QoL for women);
5. Caregivers' level of depression;
6. Caregivers' level of distress as a reaction to PWDs' neuropsychiatric and behavioural symptoms;

The apparent impact of patient measures on caregivers' QoL stresses even more the importance for professionals to aim at assessing the PWDs' QoL as well as the caregivers', particularly when patients show signs of neuropsychiatric and behavioural symptoms.

Many of these outcomes are measured as part of the routine diagnostic assessment that most specialist psycho-geriatric clinics offer to their patients. For general practitioners and other non-specialised clinicians this raises the issue of how important it is to look beyond the results of a short cognitive screening test and to consider a broader picture when confronted with patients and families who are affected by dementia.

There is a need for more intervention studies with QoL of both the patient and the informal caregiver as an outcome measure using dementia-specific scales. The few intervention studies conducted under such criteria showed that **non-pharmacological interventions** can achieve positive QoL outcomes for patients and their caregivers. Even more, non-pharmacological interventions are actually most effective if they are not only directed at the PWD but also at the caregiver.

Pharmacological studies have yet to include QoL as an outcome measure. The positive impact of ChEIs on patient QoL outcomes, such as daily functioning and cognition, however, is apparent.

There exists a large gap in knowledge regarding PWDs' and caregivers' QoL in relation to the following domains:

1. Pharmacological treatments;
2. Informal support provided by family-caregivers (direct, non-medical costs);
3. Economics, especially indirect costs such as mortality costs.

All of the above findings also apply to New Zealand. None of the 106 included studies was conducted by a researcher from New Zealand or in an institution in New Zealand.

3 Research questions, study aims and hypotheses

The literature review in the previous chapter revealed the need for a rigorous analysis of QoL in dementia, using dementia-specific assessment tools, and including not only PWDs but also their informal caregivers. These findings have led to the development of some specific research questions and objectives for this study.

3.1 Research questions

The research questions were:

1. Which factors predict QoL of PWDs and their family-caregivers?
2. Which interventions from primary and secondary care in New Zealand (Canterbury) are helpful for enhancing QoL?
3. How much do these interventions cost from an individual perspective?

Initially the third research question was not limited to individual costs (bottom-up approach) but also included the societal perspective (top-down-approach). Due to the sample size the author and her supervisors agreed in May 2009 to limit the third research question to the out-of-pocket expenses and productivity costs that family-caregivers and PWD had during the 12-month study period.

3.2 Study aims

The study aimed to:

1. Measure QoL of PWDs and their family-caregivers and potential predictive factors;
2. Examine what interventions from primary and secondary care in New Zealand (Canterbury) are helpful for enhancing QoL;

3. Measure and describe the direct and indirect costs which are related to steps that PWDs and their family-caregivers take within the New Zealand health system during the course of the disease and which have to be covered by the persons concerned.

3.3 Hypotheses

It was originally hypothesised that the following outcomes could be expected:

1. PWDs' and their family-caregivers' QoL is predicted by a number of different outcomes which are linked with each other;
2. Providing family-caregivers and PWDs with professional formal support (medical, educational, social and psychological) results in a decrease of caregivers' burden and an increase in PWDs' and caregivers' QoL and potentially in a delay of institutionalisation (thereby preventing or delaying some of the costs associated with dementia on a long-term basis);
3. Direct and indirect costs increase with disease progression, resulting in negative healthcare outcomes for PWDs and family-caregivers.

After conducting the systematic literature review these hypotheses were refined as following:

1. QoL predictors

- a. PWDs' QoL is predicted (based on level-1 studies) by depression; neuropsychiatric and behavioural symptoms; daily functioning; their general health or comorbidities prevalent in addition to the dementia; and caregivers' burden and level of distress. PWDs' QoL is not impacted by level of cognitive impairment. PWD's QoL may be predicted by the type of dementia, the illness severity; caregivers' QoL, support caregivers receive from family and friends; caregivers' health; and caregivers' perceived economic burden. PWDs' QoL is probably not influenced by caregivers' level of depression.

- b. Caregivers' QoL might be predicted (based on level-1 studies) by the type of dementia, PWDs' neuropsychiatric and behavioural symptoms, as well as caregivers' own level of distress as a reaction to PWDs' neuropsychiatric and behavioural symptoms, depression and gender (worse QoL for women). Carers' QoL is probably not predicted by PWDs' level of depression and functional impairment.

No level-1 study measured or reported on the following outcomes but it is expected that caregivers' QoL is possibly influenced by the severity of dementia, PWDs' cognition and health status. It is further predicted that caregivers' burden, support from family and friends, health and economic burden will impact on their QoL.

- c. Change over time: None of the level-1 studies conducted follow-up assessments. However, it is expected that similar QoL predictors can be observed over time (12 months) but their clinical values might deteriorate. Furthermore, it is likely that there will be times during the 12 months between baseline and follow-up assessment when caregivers will struggle more and others when they will have fewer difficulties coping with problems arising from their relatives' or friends' illness.

2. Formal support

- a. Change over time: None of the non-pharmacological level-1 studies follow-up conducted assessments for the duration of 1 year and results regarding success rates of interventions over time were inconclusive. However, it is expected that the utilisation of medical and/or educational and/or psychological and/or social supports and interventions will improve PWDs' and caregivers' QoL over time. Some QoL outcomes will worsen between baseline and follow-up despite the

utilisation of supports and interventions. But taking advantage of available support options will result in fewer negative changes.

- b. Medical: ChEIs might have a positive impact on patients' cognitive and daily functioning, particularly in mild to moderate dementia (based on level-2 studies). Early diagnosis and intervention can improve PWDs' QoL and decrease behavioural symptoms.
- c. Educational: Educational interventions (targeting neuropsychiatric and behavioural symptoms and patient mood) can improve caregiver outcomes such as depression, burden and reactivity to difficult behaviours. Such intervention can also positively impact on PWDs' neuropsychiatric and behavioural symptoms and QoL (proxy rated).
- d. Combined interventions (educational, social and psychological): Combined information and support interventions, for example seminars, day care and counselling, achieve better outcomes, such as PWDs' neuropsychiatric and behavioural symptoms and QoL, than single interventions, such as day care alone. Caregiver support programmes providing counselling, support and education can improve caregiver QoL.
- e. Non-pharmacological interventions are most effective if they are not only directed at the PWD but also at the caregiver.
- f. Utilisation of formal support: Higher levels of caregiver stress can cause an increase in the use of medical services.

3. Costs (all hypotheses based on level-2 studies)

- a. Costs (except informal care): Medical and non-medical costs of PWDs living at home, not including costs of informal caregiving time, increase with the severity of patients' cognitive impairment. Costs increase with increasing dementia severity, increasing behavioural symptoms as well as increasing functional limitations. Costs

increase more with the severity of patients' functional disability than with cognitive impairment.

- b. Direct non-medical costs (informal caregiving hours): Family and friends spend considerably more time providing care for the PWD than receiving formal care and support for their own health needs. These caregiving hours have a significant negative impact on caregivers' physical and psychological health which consequently also negatively impacts patients' QoL. Costs of informal caregiving hours (like other costs) increase with increasing dementia severity, increasing behavioural symptoms as well as increasing functional limitations.
- c. Indirect costs: Indirect costs, such as productivity costs, increase (like direct costs) with increasing dementia severity, with increasing behavioural symptoms as well as with decreasing functional and cognitive abilities.
- d. Perceived individual economic burden: Caregivers who are highly burdened consider that their financial situation is one of the most important determinants of their QoL. Caregivers of persons with moderate to severe dementia are at much higher risk to become depressed if they have a low income. Caregivers' reactions to depressive and disruptive behaviours of PWDs may put them at risk for loss of economic resources. Family-caregivers of PWDs might want to be paid for their time spent caring.

4 Methodology

4.1 Introduction

This chapter outlines how this study was conducted. The first part of this chapter describes the planning phase during which the study was set up (4.2, p. 119). The second part of this chapter explains the study design (4.3, p. 122), gives an overview of the interview process (4.4, p. 125), describes how participants were recruited (4.5, p. 129), and which inclusion and exclusion criteria were applied to enrol participants into the study (4.6, p. 131). Special attention is paid to the description of assessment tools chosen for each of the two dominant study designs: the prospective cohort study (4.7, p.132) and the economic analysis (4.10, p. 147). In addition to these two approaches some qualitative data were also collected. How these data were collected is described in section 4.11 (p. 161). Questionnaires administered to participants who discontinued before the follow-up interview are outlined in section 4.8 (p. 143). The methodology chapter is concluded by an overview of the methods chosen for analysis of the data collected (4.12, p. 163).

4.2 Study development

This study was carried out by the author, Franziska Gallrach. She conducted the study in co-operation with the memory disorders clinic and the community team, two specialist services of Older Persons Health at The Princess Margaret Hospital (TPMH) in Christchurch, New Zealand.

4.2.1 Consultations with involved institutions

Regular contact was maintained throughout the entire study with Dr. Matthew Croucher, Consultant Old Age Psychiatrist, Clinical Senior Lecturer, University of Otago; Psychiatry of Old Age Academic Unit at TPMH. Dr. Croucher not only helped developing a study recruitment design that was easy to work into staffs' clinical routines at TPMH but he also advised the author on issues arising from the collection and analysis of data.

Support was also sought from the local Alzheimer's society 'Alzheimers Canterbury'. Initially the author considered evaluation of services offered by Alzheimers Canterbury. But already during a first meeting in November 2006 it became clear that the study would take a broader approach by trying to understand quality of life (QoL) of persons with dementia (PWDs) and their caregivers. It was agreed between Lucille Ogston, at that time manager of Alzheimers Canterbury, Dr. Brian Deavoll, psychiatrist at the TPMH memory clinic, Associate Prof. Dr. Ray Kirk and Franziska Gallrach that for this new approach, participants should best be recruited through TPMH and not through the Alzheimer's society. Services offered by Alzheimers Canterbury would be included in the study as formal services and supports and how they would impact on participants' QoL. But those services would not be the only focus of this study.

During three meetings with TeleMessenger, a local software company, between May and August 2007 the author explained the study and discussed the requirements and special circumstances of this population regarding an automated phone call reminder service offered by TeleMessenger which could be used to prompt the completion of routine data. The exact wording used for the automated phone calls was determined and the system programmed accordingly. It was agreed that the author was responsible for entering new participants into the database with their names and phone numbers. TeleMessenger would set up 12 monthly phone calls to be received by each participant at the end of each month, between baseline and follow-up interview. At the end the author would also delete the entries from the database. The exact details of this service are outlined in section 4.10.3.2 (p. 157).

4.2.2 Research proposal

A research proposal was developed and constantly refined between December 2006 and May 2007. Regular meetings during that period between the author and her supervisors helped to develop a study design that was comprehensive but at the same time achievable in the timeframe given. Also, the outcomes from various consultations with the involved institutions were taken into consideration and possible difficulties and solutions foreseen were accommodated in advance

as thoroughly as possible. The research proposal was approved by the Dean of Postgraduate Studies at the University of Canterbury in June 2007.

4.2.3 Ethical approval

This study did not include any drug testing or a control group. There was only one group of participants (cohort) without any participants assigned to a waiting list. An application for ethical approval was submitted to the Upper South A Regional Ethics Committee on 26 June 2007. Locality organisational approval was sought and given from Christchurch organisations involved in this study: Older Persons Health at The Princess Margaret Hospital, Alzheimers Canterbury, TeleMessenger Solutions, and the University of Canterbury (Appendix D). The study was also supported by Maori and Pacific Health of the Canterbury District Health Board (CDHB) (Appendix E, p. 387).

- September 2007: approval by the Upper South A Regional Ethics Committee: URA/07/06/044 (Appendix C, p. 379)
- January 2008: official approval by the Upper South A Regional Ethics Committee: URA/07/06/044, 1. amendment: To include persons with severe dementia (Appendix F, p. 388)
- April 2008: official approval by the Upper South A Regional Ethics Committee: URA/07/06/044, 2. amendment: To change the recruitment process by widening the scope of identification of potential participants (So far potential participants have been drawn from the Psychiatry Service for the Elderly alone. Potential participants now will be drawn from the whole Older Persons Health service.) (Appendix F, p. 388)

One requirement for approval of the study by the Upper South A Regional Ethics Committee was to submit two progress reports, one in September 2008 and another report 1 year later in September 2009 (Appendix S, p. 427).

4.2.4 Supervision

This study was conducted under the supervision of Assoc. Prof. Ray Kirk, Director of the Health Sciences Centre at the University of Canterbury, Associate Professor, Convenor of the Postgraduate Health Information Management programme and Director of the Health Services Assessment Collaboration (HSAC), as well as Prof. Andrew Hornblow CNZM, Adjunct Professor in Health Sciences at the University of Canterbury.

4.2.5 Time frame

The study time frame is outlined below:

Dec. 2006 – May 2007:	Initial literature review, consultation, development of research design, applications ethic committee, writing of research proposal
June 2007:	Approval of research proposal by Dean of Postgraduate Studies
Sept. 2007:	Approval of study by Upper South A Regional Ethics Committee
Sept. 2007 – Aug. 2008:	Recruitment of participants
Sept. 2007 – Sept. 2008:	Baseline interviews conducted by author
Jan., Apr. 2008:	Approval of amendments by Upper South A Regional Ethics Committee
Sept. 2007 – Aug. 2009:	Diaries completed by participants
Sept. 2008 – Aug. 2009:	Follow-up interviews conducted by author
Sept. 2008:	Initial analysis of baseline data
March – Sept. 2009:	Analysis of baseline and follow-up data, diaries, qualitative data
Nov. 2008 – Mar. 2010:	Writing of thesis
31. Mar. 2010:	Completion of thesis

4.3 Overview of study design

As outlined earlier, the first and the third research questions which this study intended to answer were related to the (mainly) clinical predictors of QoL in dementia as well as to the costs for

families affected by dementia. The study design which was appropriate to answer these questions had to be very different for the clinical part as compared to the economic component. As a result this study essentially consisted of two studies: a prospective cohort study (4.7, p. 132) for the clinical aspects and an economic analysis (4.10, p. 147). In addition to these two quantitative approaches, some qualitative data were also collected in order to understand better which services and supports participants found most beneficial.

Quantitative data were collected by the author during baseline interviews and again, 12 months later, during follow-up interviews with patients and their caregivers using several questionnaire and psychometric tests. In the meantime the caregivers were asked to record how often and for how long and for which out-of pocket expenses they and the persons with dementia utilised certain medical and non-medical supports and services.

The initial diagnostic assessment of the patient at the TPMH memory clinic or through the TPMH community team took between 1.5 and 2 hours. The baseline interview conducted with patients and their caregivers usually also lasted between 1.5 and 2 hours plus an additional 30 minutes to explain the study, to answer questions and to obtain written consent. The patient's part of the interview required 10 to 15 minutes on average. Depending on the individual situation some interviews/visits lasted considerably longer (up to 4 hours), for example if there was a need to explain the study and diaries in more detail or to answer questions regarding dementia. The author often offered to split the interview into two sessions and to arrange a second appointment. The follow-up interview with patients and caregivers usually took around 2 hours. During the follow-up interview the patient was also retested using a cognitive screening test which added 15 minutes to the interview. The average time required for each assessment and questionnaire is outlined in the next section (4.4, p. 125). To fill in the diary every week was estimated to take between 5 and 10 minutes. The following figure gives an overview of the entire study, including timelines and methods applied for collecting the data.

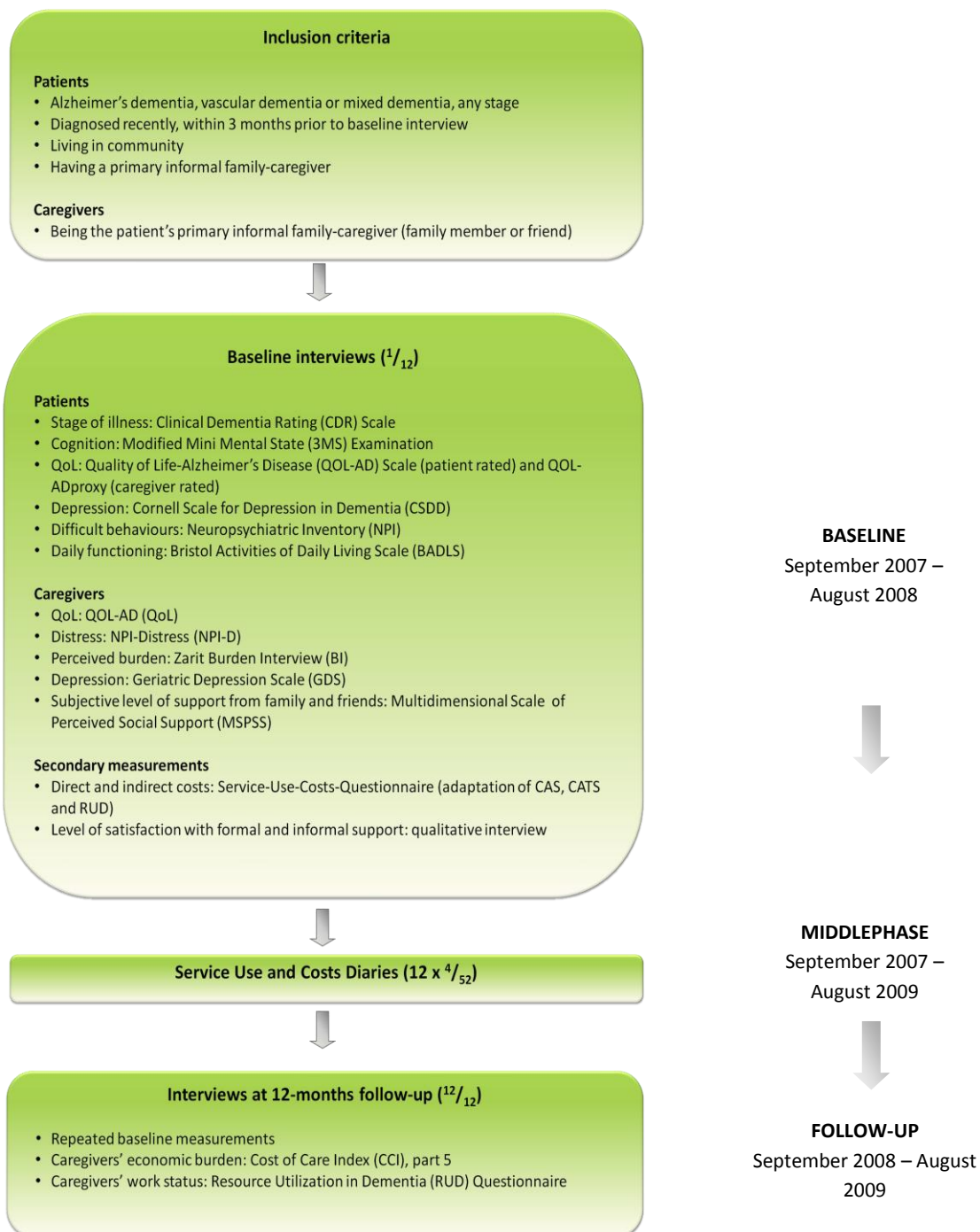


Figure 5: Study design and time line

4.4 Overview of interview process

The table below and the following three tables give an overview of the interview process, first for patients and caregivers at baseline and then at follow-up.

Table 8: Patient baseline measures, interview questionnaires and time required

Patient											
Outcome	Descriptive data	Stage of dementia	Health status		QoL		Depression	Cognition	Behaviour	Functioning	Direct and indirect costs
Measures	Socio-demographic questionnaire	CDR	Comorbidities questionnaire		QOL-ADp	QOL-ADproxy	CSDD	3MS	NPI	BADLS	Service-Use-Questionnaire
Administered by/to	A/ C	A	A/ P	A/ C	A/ P	A/ C	A/ P,C	TPMH/ P		A or (TPMH)/ C	
Time (in minutes)	10	5	5	10	10	10	15	15	15	15	10

Key. QoL, quality of life; CDR, Clinical Dementia Rating Scale; 3MS, Modified Mini-Mental State Examination; QOL-ADp, Quality of Life-Alzheimer's Disease Scale patient rating; QOL-ADproxy, Quality of Life-Alzheimer's Disease Scale proxy rating; CSDD, Cornell Scale for Depression in Dementia; NPI, Neuropsychiatric Inventory; BADLS, Bristol Activities of Daily Living Scale; A, author; C, caregiver; TPMH, The Princess Margaret Hospital.

Table 9: Caregiver baseline measures, interview questionnaires and time required

Caregiver								
Outcome	Descriptive data	Health Status	QoL	Burden	Distress	Depression	Perceived social support	Direct and indirect costs
Measures	Socio-demographic questionnaire	Comorbidities questionnaire	QOL-ADc	Zarit BI	NPI-D	GDS	MSPSS	Service-Use-Questionnaire
Administered by/to	Author/Caregiver							
Time (in minutes)	10	5	10	10	5	10	5	5

Key. QoL, quality of life; QOL-ADc, Quality of Life-Alzheimer’s Disease Scale caregiver rating; Zarit BI, Zarit Burden Interview; NPI-D, Neuropsychiatric Inventory-Distress; GDS, Geriatric Depression Scale (Mood assessment scale); MSPSS, Multidimensional Scale of Perceived Social Support.

Table 10: Patient follow-up measures, interview questionnaires and time required

Patient										
Outcome	Stage of dementia	Health status		QoL		Depression	Cognition	Behaviour	Functioning	Direct and indirect costs
Measures	CDR	Comorbidities questionnaire		QOL-ADp	QOL-ADproxy	CSDD	3MS	NPI	BADLS	Service-Use-Questionnaire
Administered by/to	A	A/ P	A/ C	A/ P	A/ C	A/ P,C	A/ P	A/ C		
Time (in minutes)	5	5	10	10	10	15	15	15	15	10

Key. QoL, quality of life; CDR, Clinical Dementia Rating Scale; 3MS, Modified Mini-Mental State Examination; QOL-ADp, Quality of Life-Alzheimer's Disease Scale patient rating; QOL-ADproxy, Quality of Life-Alzheimer's Disease Scale proxy rating; CSDD, Cornell Scale for Depression in Dementia; NPI, Neuropsychiatric Inventory; BADLS, Bristol Activities of Daily Living Scale; A, author; C, caregiver.

Table 11: Caregiver follow-up measures, interview questionnaires and time required

Caregiver									
Outcome	Health status	QoL	Burden	Distress	Depression	Perceived social support	Direct and indirect costs	Economic burden	Work status and indirect costs
Measures	Comorbidities questionnaire	QOL-AD	Zarit BI	NPI-D	GDS	MSPSS	Service-Use-Questionnaire	Cost of Care Index	Adapted from RUD
Administered by/to	Author/Caregiver								
Time (in minutes)	5	10	10	5	10	5	5	5	5

Key. QoL, quality of life; QOL-ADc, Quality of Life-Alzheimer's Disease Scale caregiver rating; Zarit BI, Zarit Burden Interview; NPI-D, Neuropsychiatric Inventory-Distress; GDS, Geriatric Depression Scale (Mood assessment scale); MSPSS, Multidimensional Scale of Perceived Social Support; RUD, Resource Utilisation in Dementia Questionnaire.

4.5 Recruitment of participants

It was intended to recruit participants by referral, through the memory clinic at TPMH, or by publicity through the quarterly newsletter of the local Alzheimer's society. However, after publication of an invitation to participate in a study which investigated QoL in dementia (Appendix H), no participants were identified. Therefore, initially, only out-patients and their family-caregivers from the memory disorders clinic at TPMH participated in this study. Right from the beginning the study design was open to changes in the recruitment process if later, during the data gathering period, it might have become apparent that the suggested approach would not identify enough potential participants. It was planned to enrol 100 patients and their 100 family-caregivers into the study during a 12-month recruitment period which started at baseline and finished just before the first participants were due for their follow-up interview.

A multidisciplinary team, which included, amongst others, a neurologist or psycho-geriatrician and a geriatric nurse, evaluated patients referred to the clinic with memory loss. A medical history was taken from each PWD. Additionally, patients underwent extensive clinical and laboratory investigations and were administered a comprehensive neuropsychological test battery. Dementia was diagnosed according to the DSM-IV criteria that define dementia as a clinical state characterised by loss of function in multiple cognitive domains. Diagnostic features include memory impairment and at least one of the following: aphasia, apraxia, agnosia, and disturbances in executive functioning. In addition, the cognitive impairments must be severe enough to cause impairment in social and occupational functioning (American Psychiatric Association, 1994). The diagnosis was usually revealed to the subjects during a second appointment at TPMH.

Patients and their caregivers were often referred to Alzheimers Canterbury during their second appointment at TPMH after being informed of the diagnosis. At this point, they were also referred to this study.

In February 2008, five months after the first baseline interviews were conducted, the author introduced the study to Susan Askew, the new manager of Alzheimers Canterbury. During this meeting it was also discussed how more participants could be identified for the study, since numbers were lower than expected. There were two reasons why recruitment through Alzheimers Canterbury directly was not an option. First of all, the majority of Alzheimers Canterbury's clients are referrals from Older Persons Health at TPMH and therefore would have already been invited to the study. Second, a change in recruitment would have required additional ethical approval which is usually a time consuming process.

However, it was agreed to use two different opportunities to promote the study further through Alzheimers Canterbury:

- i. A notice in the upcoming newsletter (in addition to the one already published 6 months earlier).
- ii. The author left a sample diary folder and an invitation at Alzheimers Canterbury for promotion of the study amongst all social workers who would advertise the study amongst clients. Staff members were asked to check with clients who had been referred through TPMH if they were aware of the study and that it was supported by Alzheimers Canterbury and to refer potential participants to the author.

Unfortunately, the call for participants was not published in the newsletter due to limited space available. The second option also did not generate more participants.

The fact that the number of participants was lower than expected was already noticed by the author early into the recruitment period which started with the first baseline interview in September 2007 and concluded 12 months later. Therefore, ethical approval was sought and given in January 2008 by the Upper South A Regional Ethics Committee to also include persons with severe dementia (Appendix F, p. 388) rather than with mild to moderate dementia only. Since the

number did not significantly increase the author applied for a second amendment which was granted in April 2008. The Upper South A Regional Ethics Committee approved to change the recruitment process by widening the scope of identification of potential participants. Until then potential participants had been drawn from the Canterbury District Health Board's (CDHB's) Psychiatric Service for the Elderly alone. Potential participants between April and September 2008 were also identified from the entire Older Persons Health Specialist Service - OPHSS (Appendix F). The author read all discharge letters of persons discharged from Older Persons Health Service between April and August 2008 to identify patients who had been treated for a health condition but in the process had also been diagnosed with dementia without being referred to the special services at TPMH. If a patient with dementia was identified the author approached the discharging doctor to obtain his/her permission to send an invitation to participate in the study to the patient and to then later contact the potential participant by phone. Discharging doctors were approached by email which had a support letter from the clinical director of Older Persons Health at TPMH, Dr. Jeff Kirwan, attached to it (Appendix I, p. 394).

Interviews were conducted by the author at baseline (usually within 2 weeks after diagnosis) and again 12 months later with the patients and their family-caregivers. The baseline was chosen to be some time after the diagnosis so the caregivers and PWDs had enough time to set up a support network if they wanted to. This was important because the interviews at baseline contained questions regarding the support these families might receive. Also, it allowed participants to reflect on the diagnosis which can cause severe distress in patients as well as their caregivers. Interviews were conducted at the University (Health Sciences Centre), or at another location convenient to the patients and their families, such as participants' homes.

4.6 Inclusion and exclusion criteria

A multidisciplinary team, including a neurologist, evaluated out-patients referred to the clinic with memory loss. Consecutive out-patients and their caregivers were eligible if a neurologist judged

the patient to have mild to moderate (and later, severe) dementia and the caregiver to be capable of study participation. The stage of illness was a clinical decision based on the functional impairment of the PWD. Only caregivers with primary responsibility for the PWD's care were eligible. Caregivers and PWDs had to be able to understand and speak English at least on a basic level. There would have been an interpreter available if requested by the participants (for example, for Maori).

Subjects were recently diagnosed with dementia, that is, within 3 months prior to the baseline interview. They and their family-caregivers sought first time help from the dementia society 'Alzheimers Canterbury' in Christchurch. Subjects were also included if they decided (despite referral) not to get in touch with Alzheimers Canterbury but still received social and/or medical support initiated by TPMH.

4.7 Prospective cohort study

The first study objective was to measure QoL of PWD and their family-caregivers for which a multi-dimensional approach was chosen. Measurements of the primary study outcomes combined some concepts of QoL instead of using only one QoL scale. The global QoL as well as various QoL dimensions (cognition, behaviour, depression, functioning and burden) were assessed. In addition, costs of caring for PWDs who live at home were estimated. It was anticipated, and later confirmed by the systematic literature review, that a multi-dimensional approach of QoL would result in more reliable outcomes compared to a more narrow approach where some of these aspects might have been omitted. Such an approach seemed even more important since this study focused on a wider range of dementias and included persons at different stages of the disease continuum. This multi-dimensional approach also matched the measurements that are routinely obtained as part of the diagnosis process at TPMH, and the study had therefore minimal impact on staff time. The following sections describe every assessment tool used during the study. The questionnaires can also be found in Appendices L (p. 399) and M (p. 416).

4.7.1 Socio-demographic data

The study design included the collection of descriptive socio-demographic data from both the PWD and their caregiver. Data were collected only at the beginning of each baseline interview and not repeated during the follow-up interview. The following characteristics of participants were obtained: age, gender, ethnicity, relationship, education, occupation, employment, joint income, being holder of a community services card.²⁹

4.7.2 Clinical measures of patient quality of life

Clinical measures of patient QoL at baseline and follow-up interview included: stage of dementia, cognitive impairment, QoL *per se*, depression, neuropsychiatric and behavioural symptoms, daily functioning (ADL/IADL) and health (comorbidities).

4.7.2.1 Stage of dementia: Clinical Dementia Rating Scale (CDR)

The CDR was developed for assessing the severity of dementia (Hughes, Berg, Danziger, Coben, & Martin, 1982; Meuser, 2001; Morris, 1993). It was developed primarily for use in PWDs of the Alzheimer type but it can also be used to stage other dementing illnesses. The CDR is a five-point rating scale ranging from CDR-0 representing no cognitive impairment to CDR-0.5 (very mild dementia), CDR-1 (mild dementia), CDR-2 (moderate dementia) up to CDR-3 which indicates severe dementia. “In assigning a Global CDR, the six domains that are used to construct the overall CDR table are each scored individually. The six domains are: Memory, Orientation, Judgment and Problemsolving, Community Affairs, Home and Hobbies, and Personal Care” (Meuser, 2001). The rating of each of these domains is based on the PWD’s cognitive ability to function in these areas and not influenced by physical frailty. “It is not typically the case that all of the six domains are in the same severity range [...] because dementing illnesses, such as dementia of the Alzheimer type, do not always progress uniformly in all domains at the same time” (Meuser, 2001). To build the overall sum the author used the following website

²⁹ It enables the holder to obtain certain health care services for free or at a cheaper rate.

<http://www.biostat.wustl.edu/~adrc/cdrpgm/index.html> which allows the user to enter the six domain scores and to submit them to a SAS computer programme which returns the overall sum within seconds. This website was set up by the “Washington University Alzheimer's Disease Research Center”, where the CDR had initially been developed in 1979. This page is free for anyone to use.

Initially, while only persons with mild to moderate dementia were referred to the study, the stage of disease was a clinical decision based on the patient's cognitive impairment (memory loss plus at least one other functional domain impairment) made by the assessing psychiatrist or specialist nurse and not by the author. However, the CDR was rated at both baseline and follow-up interview, in order to achieve comparability between both data sets.

4.7.2.2 Cognition: Modified Mini-Mental State Examination (3MS)

The Mini-Mental State Examination (MMSE) is a widely used screening test for dementia to stage the cognitive severity of the disease by testing the following components of cognitive functioning: concentration, orientation, language, praxis, and memory (Folstein, et al., 1975). With scores ranging from 30 to 0, the following cut-off levels have been suggested: ≥ 27 = no cognitive impairment; 21 – 26 = mild; 11 – 20 = moderate; ≤ 10 = severe (Folstein, Folstein, McHugh, & Fanjiang, 2001).

The 3MS (Teng & Chui, 1987) incorporates four added test items, more graded scoring, and some other minor changes. These modifications are designed to sample a broader variety of cognitive functions, cover a wider range of difficulty levels, and enhance the reliability and validity of the scores. Similar to the MMSE the 3MS is administered quickly and easily. It broadens the score from 0 – 30 to 0 – 100, with higher scores denoting better cognitive function. It has shown greater sensitivity over the MMSE (Teng & Chui, 1987, 1996). The authors of the 3MS never suggested any cut-off scores. However, in a large population study the cut-off point of 77/78, indicating the presence of cognitive impairment, has been successfully applied (McDowell, Kristjansson, Hill, & Hébert, 1997). From the same study it can be concluded that the following scores might be a

sensible choice in order to determine PWDs' level of cognitive impairment: 100 – 78 = no cognitive impairment; 68 – 77 = mild; 38 – 67 = moderate; ≤ 37 = severe. The 3MS was administered during the routine diagnostic process at TPMH. Therefore, at baseline, the author only had to assess those patients using the cognitive screening test who had not been enrolled through the memory clinic or community team service.

By assessing PWDs' level of cognitive impairment separately from the overall stage of dementia the researcher acknowledges that while a person's cognitive ability will impact on his/her ability to function in the domestic and social environment the level of functioning is more comprehensively reflected in a staging tool such as the CDR. Also, as shown in the literature review, cognition alone seems to be less likely to predict QoL of PWDs.

4.7.2.3 Quality of life: Quality of Life-Alzheimer's Disease Scale (QOL-ADp, proxy)

The QOL-AD was developed by Logsdon, Gibbons, et al. (1999; 2002) and conducted by the author at baseline and follow-up. The QOL-AD uses both patient and caregiver reports to assess QoL. This is a 13-item patient and caregiver measure of quality of life, which covers the following domains: physical health, energy, mood, living situation, memory, family, marriage, friends, tasks, fun, money, self and life as a whole. Thirteen items are rated on a 4-point Likert scale, with 1 being poor and 4 being excellent, with a total score of between 13 and 52.

The scale was developed based on a literature review on the assessment of QoL in other chronically ill populations. The scale has shown excellent internal consistency with a Cronbach's alpha coefficient of 0.82 (Thorgrimsen, Selwood, et al., 2003) and of 0.84 (Logsdon, et al., 2002) for patient reports and with a Cronbach's alpha coefficient of 0.86 for caregiver ratings (Logsdon, et al., 2002). Validity of patient and caregiver reports across cognitive levels was supported by Pearson's correlation with measures of depression ($r = -.41$ to $-.65$), day-to-day functioning ($r = -.10$ to $-.45$), and pleasant events frequency ($r = .18$ to $.51$). Intra-class correlation between patient and caregiver reports was positive across all cognitive levels ($r = .14$ to $.39$) (Logsdon, et al., 2002).

Ettema and colleagues (2005) found in their review of QoL instruments used in dementia, that the application of this scale was limited to patient-caregiver dyads living in the community, and patients with mild to moderate severity: MMSE > 10. But there is also evidence for the validity and reliability of the QOL-AD in people with MMSE scores of 3 to 11 (Hoe, et al., 2005).

In this study, ratings of the patient's QoL were obtained from both the patient (QOL-ADp) and the caregiver (QOL-ADproxy).

4.7.2.4 Depression: Cornell Scale for Depression in Dementia (CSDD)

The CSDD (Alexopoulos, et al., 1988) was administered by the author at baseline and follow-up. The CSDD is a 19-item instrument specifically designed for the rating of symptoms of depression in demented patients. Items were constructed so they can be rated primarily based on observation. The instrument is administered by a clinician (here: the author) using information from interviews with both the patient and a caregiver. The severity of each item is rated according to three explicitly defined grades: absent, mild or intermittent, and severe. The scale is administered in two steps. First the clinician interviews the patient's caregiver on each of the 19 items, and then briefly interviews the patient. The caregiver is instructed to base his report on observations of the patient's behaviour during the week prior to the interview. After interviewing the patient, if there are any large discrepancies between the clinician's observations and the caregiver's report, then the clinician will again interview the carer to clarify the reason for disagreement. The CSDD is scored based on the clinician's final judgement. The item scores are summed: < 6: absence of significant depressive symptoms; > 10: probable major depression; > 18: definite major depression. Total time for the administration is approximately 30 minutes: 20 minutes with the caregiver and 10 minutes with the patient. The scale has shown high interrater reliability (Cohen's kappa of 0.67), internal consistency (Cronbach's alpha coefficient of 0.84) and sensitivity (Alexopoulos, et al., 1988).

The CSDD requires more time to complete than many other scales for determining depression. It requires the participation of a caregiver who has a thorough knowledge of the patient's status over the previous week. It is more likely to yield meaningful results than measures which rely only on patient responses to questions due to the inability of cognitively deficient patients to respond adequately to other surveys.

4.7.2.5 Neuropsychiatric and behavioural symptoms: Neuropsychiatric Inventory (NPI)

The NPI (Cummings, et al., 1994) was included in the assessment during the routine diagnostic process at TPMH by staff at baseline. The author administered the NPI at baseline to caregivers of patients who had been enrolled from the broader Older Persons Health in Canterbury and at follow-up to all caregivers.

The NPI assesses 10 behavioural disturbances occurring in dementia patients: delusion, hallucination, depression, anxiety, agitation/aggression, euphoria, disinhibition, irritability/lability, apathy, and aberrant motor activity. The NPI uses a screening strategy to minimise administration time, examining and scoring only those behavioural domains with positive responses to screening questions. Both the frequency (from 1-occasionally to 4-very frequently) and the severity (from 1-mild through 2-moderate to 3-severe) of each behaviour are determined. Domains with negative response to the screening question are not explored, while data regarding the characteristics, severity, and frequency are examined for each domain with a positive response. A total domain score is calculated by multiplying frequency and severity. A global score for the NPI can be generated by summing the total scores (frequency multiplied by severity) of the individual subscales. Information for the NPI is obtained from a caregiver who is familiar with the patient's behaviour. The interview is best conducted with the carer in absence of the patient to generate an open discussion of behaviours that may be difficult to describe with the patient present. The instrument has shown to be both valid and reliable (Cronbach's alpha between 0.87 and 0.88 for severity and frequency of items) (Cummings, et al., 1994). Test-retest and interrater reliability have been evaluated, and the tool was found to be reliable (Cummings & Masterman, 1998).

4.7.2.6 Daily functioning: Bristol Activities of Daily Living Scale (BADLS)

The BADLS (Bucks, Ashworth, Wilcock, & Siegfried, 1996) was also administered by staff during the routine diagnostic process at TPMH at baseline. The author obtained the BADLS score at baseline for patients that had come from the broader Older Persons Health in Canterbury and at follow-up for all patients.

The Bristol Activities of Daily Living Scale has been developed specifically for use with people with dementia (Bucks, et al., 1996). It is rated by a caregiver and consists of 20 daily-living abilities. For the analysis these 20 abilities were split into two different domains of patients' functional competence: basic activities of daily living (ADLs) and more complex instrumental activities of daily living (IADLs):

1. ADLs: eating, drinking, dressing, hygiene, teeth, bath/shower, toilet/commode, transfer, mobility, orientation to time, orientation to place, communication;
2. IADLs: preparing food, preparing drink, telephone, housework/gardening, shopping, finances, games/hobbies, transport (driving).

The distinction between these two domains is comparable to the World Health Organization's distinction between impairment which is a physical restriction and disability which refers more to a social role limitation (World Health Organization, 2010).

Severity judgements range from independence (score 0 – no help required) through to dependence (score 3 – unable even with supervision), rated on a four-point scale. This produces a total score range between 0 and 60 points. Additionally, caregivers can choose to score an item as not applicable, if the PWD never engaged in that activity before the illness. These not applicable items are scored 0 (Bucks & Haworth, 2002). The scale has good internal consistency as well as face- and construct validity (Bucks, et al., 1996). It correlates well with MMSE and has good test-retest reliability (Cohen's kappa of 0.41 or more for 19 of the 22 items) (Bucks, et al., 1996).

4.7.2.7 Health status: Comorbidities p and proxy

A 5-point Likert scale was developed to measure if participants' QoL was at the time of the interview significantly worsened by any of the following physical or mental health problem(s): heart attack, heart failure, stroke, angina, emphysema/ asthma, shortness of breath, headache, impaired vision, impaired hearing, dizziness, parkinsonism, falls, skin problems, high or low blood pressure, diabetes, broken bones, arthritis, other joint problems, nausea, bowel problems, incontinence, kidney failures, thyroid disease, surgery, cancer, any other causes (of chronic pain). The question was, when a certain health condition was identified, how severely it impacted upon the participant's QoL ranging from 1 (not at all) to 5 (quite severe). Points were added with a higher sum indicating a higher number of comorbidities or a more severe impact of only a single or a few conditions. Data regarding PWDs' health were collected from both patients (Comorbidities p) and caregivers (Comorbidities proxy).

For PWDs this questionnaire was developed to better understand if their QoL was significantly worsened by any other health condition besides their impaired cognition. For caregivers this scale was used as a generic health assessment tool. The scale was also administered to caregivers to obtain a proxy rating of patients' general health aside from their dementia.

There exist a number of validated scales to assess comorbidities but they were not suitable for this study. Often those scales would have taken too long to be administered and since the interview already required more than 1 hour for completion, the author felt that a scale regarding comorbidities should not take more than 5 or 10 minutes to administer. In addition, the medical knowledge necessary for correct completion of those questionnaires would have required a medical professional from TPMH. The entire study design was developed to have the least impact on the daily routines of staff at TPMH, otherwise the cooperation might have been compromised and therefore fewer participants identified. Instead, this scale was developed by the author with guidance from Dr. Matthew Croucher.

4.7.3 Clinical measures of caregiver quality of life

Clinical measures of caregiver QoL at baseline and follow-up interview included: QoL *per se*, burden, distress caused by PWDs' neuropsychiatric and behavioural symptoms, depression, health, the subjective level of support from family and friends and the perceived economic burden.

4.7.3.1 Quality of life: Quality of Life-Alzheimer's Disease Scale (QOL-ADc)

In this study the caregivers' QoL was assessed with the same instrument (QOL-AD) as the patients' QoL. The QOL-AD has been used to successfully measure the caregivers' QoL (Shin, et al., 2005). The QOL-AD was administered by the author at baseline and follow-up.

4.7.3.2 Subjective burden: Zarit Burden Interview (BI)

The burden associated with the care of a demented person has been examined in several studies and numerous measures have been carried out (Vitaliano, Young, & Russo, 1991). However, the BI, developed by Zarit, Reever and Bach-Peterson (1980) remains the most commonly used scale to measure caregiver burden in dementia (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005). The BI has been designed to assess the stresses experienced by family-caregivers of elderly and disabled persons. It can be completed by caregivers themselves or as part of an interview. Caregivers are asked to respond to a series of 22 questions about the impact of the patient's disabilities on their life. The items are derived from clinical and research experience with dementia caregivers. The scale has content validity and takes into account common areas of concern such as health, finances, social life and interpersonal relations. For each item, caregivers are asked to indicate how often they have felt that way: never, rarely, sometimes, quite frequently, or nearly always. The BI is scored by summing the responses of the individual items. Higher scores indicate greater caregiver distress: 0 – 21 (no – little burden); 21 – 40 (mild – moderate burden); 41 – 60 (moderate – severe burden); 61 – 88 (severe burden). The scale has high internal consistency with a Cronbach's alpha coefficient of 0.91 and good test-retest reliability with Cohen's kappa of 0.71 (Gallagher, Rappaport, Benedict, Lovett, & Silven, 1985).

The Zarit BI was conducted by the author at baseline and follow-up.

4.7.3.3 Distress: NPI - Distress (NPI-D)

The NPI-D has been developed by Kaufer, et al. (1998) as an “adjunct scale to the NPI for assessing the impact of neuropsychiatric symptoms in Alzheimer's disease patients on caregiver distress” (p. 210). The authors found the NPI-D to be a reliable and valid measure with good test-retest (Pearson's correlation: $r = .92, p < .001$) and interrater reliability (Pearson's correlation: $r = .96, p < .001$) (Kaufer, et al., 1998). The NPI assesses 10 behavioural disturbances occurring in dementia patients using 10 subscales. For each of the behaviours identified caregivers were asked to rate their level of distress caused by a certain behaviour ranging from 1 (minimal) to 5 (severe or extreme distress). A global score of distress was generated by summing the scores of the individual subscales.

The NPI-D was administered to caregivers at baseline and follow-up.

4.7.3.4 Depression: Geriatric Depression Scale (GDS)

Family-caregivers of relatives with AD are at high risk for psychological distress, with rates of clinical depression and depressive symptoms far exceeding those for age matched comparison groups (Schulz, O'Brien, Bookwala, & Fleissner, 1995). The GDS is a brief, 30-item questionnaire in which participants are asked to respond by answering yes or no in reference to how they felt over the past week. The number of questions answered positive is added up. A depression may be present if a participant responded more than 10 times with 'yes'. The scale was originally developed for use with older persons (Yesavage, et al., 1982) but has since been widely used in a broad population including younger and older family-caregivers of persons with dementia (Covinsky, et al., 2003; Mittelman, Roth, Coon, et al., 2004). The sensitivity and specificity, and the convergent and criterion validity of the GDS are reported to be excellent (Korner, et al., 2006; Yesavage, et al., 1982).

The GDS was administered to caregivers by the author at baseline and follow-up.

4.7.3.5 Health status: Comorbidities c

In this study the caregivers' general health was assessed with the same 5-point Likert scale developed to measure caregivers' health status. The question was, when a certain health condition was identified, how severely it impacted upon the participant's QoL ranging from 1 (not at all) to 5 (quite severe). Points were added with a higher sum indicating a higher number of comorbidities or a more severe impact of only a single or a few conditions.

4.7.3.6 Social support: Multidimensional Scale of Perceived Social Support (MSPSS)

The demands of caregiving may lead to the abandonment by the caregiver of hobbies and social activities, in addition to the social interaction lost by giving up work (Brodaty, 2007). Level of social support and perceived isolation can be measured with the MSPSS (Zimet, Dahlem, Zimet, & Farley, 1988). It is a 12-item measure comprising three aspects of perceived social support - that derived from family members, from friends, and from significant others. Items are measured on a 7-point-Likert-scale from 1 (strongly disagree) to 7 (strongly agree). A higher score indicates increased levels of perceived social support. The score on individual items on the MSPSS are summed to calculate a total score (maximum of 84 points). Scores on the four items that comprise each of the three subscales are also summed to calculate three single scores for family members, friends, and significant others (maximum 28 points each). Canty-Mitchell and Zimet (2000) assessed the reliability and validity of the MSPSS instrument. The Cronbach's alpha coefficient for the entire MSPSS was 0.93; the Cronbach's alpha coefficient of the three subscales of family, friends and significant other were 0.91, 0.89 and 0.91 respectively. Correlation coefficients were used to assess the validity of the MSPSS instrument by comparing it to the Adolescent Family Caring Scale (AFCS). The results showed that for the family subscale the correlation was $r = .76$ ($p < .001$), for the friends' subscale it was $r = .33$ ($p < .001$), and for the significant other subscale was $r = .48$ ($p < .001$) (Canty-Mitchell & Zimet, 2000).

The MSPSS was administered to caregivers by the author during baseline and follow-up interviews.

4.7.3.7 *Coping ability scale*

Since data for this study were only collected twice, at baseline and then 12 months later, it was agreed between the author and her supervisors that a tool was needed which would increase understanding of the events occurring and processes evolving in between these two points in time. It was also hypothesised that QoL would not be decreasing consistently only because AD is an illness where patients' functioning overall consistently decreases. Therefore, a 4-point Likert scale was developed asking caregivers if there was a time within the past 12 month where they had been struggling to care for their relatives with answers ranging from 1 (a little) to 4 (extreme). An open ended question was included regarding the reasons for these difficulties. The same schema was used to develop a scale on the positive caregiving experiences where caregivers could rate their ability to look after their relatives ranging from 1 (poor) to 4 (excellent). In the process of administering these coping scales, it became apparent that their reliability was questionable. However, the open ended questions provided very insightful qualitative data.

4.8 Discontinuing participants

At the beginning of the data collection period it had to be anticipated that it would not be possible to collect follow-up data from all study participants. If participating patients changed into residential care within the 12 months between baseline and follow-up interview they did not fulfil the study inclusion criteria any longer. Caregivers were then asked to fill in one short questionnaire regarding the change of the PWD's living accommodation which was derived from the Resource Utilization in Dementia Instrument – RUD, asking for the type of long-term care as well as the prior reason for institutionalisation. Caregivers were also asked to fill in the questionnaire regarding their current work status (part of RUD), the Economic Questionnaire (section 4.10.4, p. 160), as well as the self-developed questionnaire on their coping abilities.

4.9 Assessment of formal interventions in New Zealand (Canterbury)

The second research objective was to examine what interventions from primary and secondary care in New Zealand are helpful for enhancing QoL. In order to answer the second research question of this study it was necessary to define the term “intervention”.

Intervention: “an activity or set of activities aimed at modifying a process, course of action or sequence of events, in order to change one or several of their characteristics such as performance or expected outcome” (World Health Organization, 2000).

For this study an intervention was defined as a treatment benefit which is a certain dose of medical and/or educational and/or psychological and/ or social support.

The treatment benefit was measured in two different ways. Firstly, a treatment benefit was considered as given if the intervention was actually utilised by PWD and caregivers. This was measured in hours rather than number of utilisations. The next section on the economic evaluation, the third part of this study, will explain more in detail how participants’ service utilisation was measured.

Secondly, in a clinical context, a treatment benefit was shown if PWDs’ or their caregivers’ QoL and/or QoL outcomes remained stable or even improved from baseline to follow-up as compared to decreased. All clinical QoL and their assessments have been described in the previous section of this chapter as integral part of the prospective cohort study.

Interventions from a variety of professional areas and on different levels of interaction/participation were assessed:

a) Medical:

- Medication (mental health and dementia medication)
- Professional out-of-home care (overnight hospitalisation, GP and specialist doctor visits, psycho-geriatrician, nurse visits)
- Professional in-home care (visiting nurse, personal care assistance, domestic assistance, meals-on-wheels)

b) Educational:

- Programmes to educate caregivers about the disease process (education meetings 1 per month, seminars)
- Training to improve coping skills or problem solving (Making-A-Difference-Course=10 training-units)

c) Social (developing support system):

- Support groups offered by Alzheimer Society (Memory Group, Carers' Group)
- day-care programmes
- sitter service

d) Psychological (counselling):

- Social worker from Alzheimer Society
- Psychologist
- Other

The following table gives an overview of all types of formal supports and interventions measured and of the different methods used for their assessment.

Table 12: Overview of formal care utilisation items and methodology

			QUESTIONNAIRE				DIARY		NURSE MAUDE	
			PWD		Carer		PWD	Carer	PWD	
			Baseline	Follow-up	Baseline	Follow-up	1 year	1 year	Baseline	Follow-up
1. Medical support	Medication	ChEIs	✓	✓			✓	-		
		Mental health	✓	✓	✓	✓	✓	✓		
	Out-of-home care	Overnight hospitalisation	✓	✓	✓	✓	✓	✓		
		GP	✓	✓	✓	✓	✓	✓		
		Psycho-geriatrician (TPMH)					✓			
		Specialist	✓	✓	✓	✓	✓	✓		
	In-home care	Nurse					✓	✓		
		Visiting nurse	✓	✓					✓	✓
		Personal assistance	✓	✓					✓	✓
		Domestic assistance	✓	✓					✓	✓
		Meals-on-wheels	✓	✓						
2. Education	Alzheimers Canterbury	Monthly seminars/ 'Making a Difference' courses						✓		
3. Social support	Alzheimers Canterbury	Memory group					✓			
		Carers' group						✓		
	Others	Day care	✓	✓						
		Sitter service	✓	✓						
4. Psychological support	Counselling	Social worker Alzheimers Canterbury					✓	✓		
		Psychologist					✓	✓		
		Other					✓	✓		

4.10 Economic analysis

The second research aim was to examine what interventions from primary and secondary care in New Zealand are helpful for enhancing QoL in dementia followed by the third research objective, which was to examine how much these interventions cost. More specifically, the third objective was to measure and describe the direct and indirect costs which are related to steps that PWD and their family-caregivers take within the New Zealand health system during the disease and which have to be covered by the persons concerned. This last research aim took the evaluation of available interventions beyond clinical outcomes. In addition to the primary clinical outcomes, a second part of this study was therefore an economic evaluation of those interventions. An **economic evaluation** was defined as “the comparative analysis of alternative courses of action in terms of both their costs and consequences” (M. F. Drummond, et al., 2005). In representation of this definition, the second and third research objectives were to identify, measure, value, and compare the outcomes and costs of interventions available from primary and secondary care for PWDs and their families. However, as described at the beginning of this chapter, this economic evaluation was limited to the out-of-pocket expenses to be covered by the study participants as well as productivity costs using a bottom-up-approach.

4.10.1 Cost definitions

A recent report issued by Alzheimers New Zealand explained two main methods are distinguished for estimating direct health system costs:

Top-down “disease cost data can be derived from central data collection agencies, where these agencies exist” (Access Economics, 2008);

Bottom-up “cost estimates use surveys, diaries and other cross-sectional or data gathering tools to accumulate information from either a single study or multiple sources” (Access Economics, 2008).

The report (Access Economics, 2008) further clarifies:

The advantage of the top-down methodology is that cost estimates for various diseases will be consistent, enhancing comparisons and ensuring that the sum of the parts (health system costs of each disease) does not exceed the whole (total expenditures on health care in New Zealand). The advantage of the bottom-up methodology is that it can provide greater detail in relation to specific cost elements and the same study can be extended to capture information about indirect cost elements as well as direct cost elements. (p. 15)

The World Health Organization (1999) has published the following definitions for different costs:

Costs: “value of the resources used in an activity, also the benefits sacrificed through a particular event of choice of action rather than another”;

Direct costs: “all the goods, services and other resources that are consumed in the provision of a particular service or area (such as hospital supplies), including medical costs (such as payments to providers, material) and non-medical costs (such as transportation to hospital)”;

Indirect costs: “total sum of morbidity costs (goods and services not produced by the patient because of the illness), mortality costs (goods and services the person could have produced had the illness not been incurred and the person not died prematurely), and **productivity cost** (related to lost productivity incurred by an employee who leaves work to provide care for the patient)”;

Intangible costs: “usually used in economic evaluation, to indicate features like pain, anxiety or grief, which cannot be directly quantified in monetary terms”.

These definitions were applied throughout the study even though Drummond, et al. (2005) argued that these terms should be avoided since they have not been used consistently across studies in the past. However, these terms are widely used in publications which deal with economic aspects of dementia.

4.10.2 Assessment of direct and indirect costs

In this study, **direct medical costs** for PWD and family-caregivers included:

- Medication (dementia and other mental health drugs)
- Consultation with health professional (GP, psychiatrist/ geriatrist, nurse, other specialist)
- *Paid care provided by a professional caregiver (visiting nurse, help with personal care)*³⁰
- Counselling (*social worker, Alzheimer Society, psychologist, other*)

Direct non-medical costs for PWD and family-caregivers included:

- Meals-on-wheels
- Time spent on informal care (unpaid care provided by a family-caregiver)
- *Domestic assistance*
- *Day care, sitter service*
- *Support group meetings, Alzheimer society seminars*

Indirect costs included:

- Productivity costs (lost productivity of a family-caregiver due to the care of relative or friend with dementia).
- At follow-up: Work status caregiver (part of the Resource Utilization in Dementia Instrument – RUD) which determines change between baseline and current employment status, for example, cut-back in overall working hours in order to accommodate the patient's increased need for care.

Most people with dementia will be affected in later life when they are usually no longer employed.

It was therefore assumed that the mortality costs would not have a significant impact on the overall dementia related costs in this study. For that reason, the mortality costs were not measured. The morbidity costs were not assessed neither because this study focused on illness-

³⁰ *Italic writing indicates that these services were assessed in terms of their utilisation but not quantified in terms of their costs since these services are freely available for PWDs who have been assessed and diagnosed through The Princess Margret Hospital's geriatric specialists (like all participating PWDs).*

related costs. A decrease at follow-up in PWDs' and caregivers' QoL can be understood as **intangible costs**.

Costs in this study were estimated using the **gross costing method** in which the utilisation of important types of care are summed and then multiplied by a unit cost for each type of care. **Table 13** shows the unit costs and their sources. These unit costs were based on national or regional averages of charges or expenditures for health care services in 2007.

Table 13: Overview of unit costs and source of information

Cost items	Unit costs	Source
Paid care provided by professionals:		
Visiting Nurse	Free ³¹	
Support worker for personal and domestic assistance	Free	
“Meals-on-wheels”	NZ \$7.72/delivery	Age Concern Canterbury: average price of a list of nine different regional service providers in 2009 (Age Concern Canterbury, 2009)
Adult day-care service	Free	
Consultation with GP	NZ \$29.00/visit	Partnership Health Canterbury Te Kei o Te Waka (Partnership Health Canterbury - Te Kei o Te Waka)
One-to-one counselling:		
Social worker Alzheimers Canterbury	Free	
Psychologist	NZ \$--/hour	individual results depending on the caregiver’s information
Group meetings (support groups, Alzheimers Canterbury seminars...)	Free	
Medication:		
Dementia medication	NZ \$230.00/monthly prescription of dementia medication (retail price)	At the time of study conduction the price varied between NZ \$200 to NZ \$260. Therefore an average price was used here.
Other mental health medication	NZ \$--/prescription	individual results depending on the caregiver’s information
Unpaid care provided by family-caregiver	NZ \$24.85/hour	Replacement wage method: rate adopted from Access Economics NZ report 2008
Productivity costs of the caregiver	NZ \$90.00/day of work loss due to care	minimum wage for employees aged 18 years and over for an eight hour day before tax on 1 April, 2007 (Department of Labor - Te Tari Mahi)
Other (such as transport)	NZ \$/hour or unit	individual results depending on the caregiver’s information

Table 14 shows for which items costs were calculated and how the necessary information for these calculations were collected. The methodology will be explained in detail in the following sections. The order in which the cost items are listed in this table is the same order in which the costs were assessed depending on the different instruments utilised to collect these data.

³¹ “Free”, that is no out-of-pocket expenses occurred for the participants. However, these services create costs for the health system from a societal point of view.

Table 14: Overview of cost types assessed, unit prices applied and methods of assessment used

					QUESTIONNAIRE				DIARY	
Type of costs					PWD		Carer		PWD	Carer
				Questionnaire	DIARY	Baseline	Follow-up	Baseline	Follow-up	1 year
Direct medical costs	Medication	ChEIs	NZ \$230.00/ monthly prescription	Out-of-pocket	✓	✓	n. a.	n. a.	✓	n. a.
		Mental health	not assessed	Out-of-pocket	not assessed	not assessed	not assessed	not assessed	✓	✓
	Out-of-home-care	GP	NZ \$ 29.00/visit	Out-of-pocket	✓	✓	✓	✓	✓	✓
		Specialist	not assessed	Out-of-pocket	not assessed	not assessed	not assessed	not assessed	✓	✓
		Nurse	not assessed	Out-of-pocket	not assessed	not assessed	not assessed	not assessed	✓	✓
Direct non-medical costs	In-home-care	Meals-on-wheels	NZ \$ 7.72/delivery	n. a.	✓	✓	n. a.	n. a.	not assessed	n. a.
Direct medical costs	Counselling	Psychologist	not assessed	Out-of-pocket	not assessed	not assessed	not assessed	not assessed	✓	✓
		Other	not assessed	Out-of-pocket	not assessed	not assessed	not assessed	not assessed	✓	✓
Direct non-medical costs	Informal care	Care provided by family-caregiver	NZ \$24.85/hour	not assessed	n. a.	n. a.	✓	✓	n. a.	not assessed
Indirect costs	Productivity costs	Lost productivity of caregiver due to care responsibilities	NZ \$90.00/day	NZ \$90.00/day	n. a.	n. a.	✓	not assessed	n. a.	✓
Direct non-medical costs	Other	such as transportation, annual membership Alzheimers Canterbury	not assessed	Out-of-pocket	not assessed	not assessed	not assessed	not assessed	✓	✓

4.10.3 Gross costing method using an adaptation of CAS, CATS and RUD

Two main methods were used to obtain the cost data: a questionnaire and a diary. First of all, the care services provided by paid professionals was measured at baseline and after 12 months using the Caregiver Activities Time Survey – CATS (Clipp & Moore, 1995) and the Caregiver Activity Survey – CAS (Davis, et al., 1997). Both surveys have shown good test-retest reliability, are significantly correlated with the severity of the patients’ cognitive and non-cognitive symptoms, and were responsive to change in a clinical trial of a cholinesterase inhibitor (Clipp & Moore, 1995; Davis, et al., 1997; Marin, et al., 2000). However, studies have suggested that carers had difficulties using the CATS to provide information on informal care inputs (Davis, et al., 1997; Raftery, Stirling, & Cuncill, 1999). The CAS is simpler and more straightforward to use. It is designed to measure the time caregivers spend helping Alzheimer’s patients with their day-to day activities. However, it does not enable detailed data to be collected on types of formal care input. Therefore, a mix of both questionnaires was used for this study. A list of services – derived from the CATS (i.e. visiting nurse, support worker for personal and domestic assistance, “meals-on-wheels,” day care service, and others) was given to the caregivers. They were asked to report for each service (1) the number of times the service was received in the last two weeks and (2) the average time spent per visit.

The second part of the questionnaire – derived from the CAS – measured the unpaid care provided by the family-caregiver. The informant was asked to estimate the time spent in a typical day for five categories of care (supervision, transportation, dressing, eating, and looking after the PWD’s appearance). The informant only included activities that were new since the onset of dementia. The time spent in each of the categories and services was summed and then annualised. A **replacement wage method** was used to estimate the economic value of unpaid care giving. In this approach, the unit cost of unpaid caregiving time was the hourly wage of a worker who would need to be hired to provide the same care that an unpaid family-caregiver is providing (Murman, et al., 2002). In Economics, it is more common to use the concept of opportunity costs.

That is, how much the caregiver would be earning if he/she worked for pay instead of taking care of the PWD. This method gives different results for caregivers with different 'opportunity costs' (that is, foregone wage). So, for example, a transplant surgeon would have higher costs of staying at home with a PWD patient than a supermarket cashier. However, the replacement wage method was chosen despite these considerations since it could be expected that a majority of caregivers in this study would be spouses who would no longer be part of the workforce.

The carer rate of NZ \$24.85 per hour was adopted from the 2008 New Zealand economic dementia report (Access Economics, 2008). The authors based this rate "on average total hourly earnings for the industry division 'Health and Community Services' in 2007 and estimated for 2008 based on historical growth rates" (p. 40).

Additionally, the number of outpatient health professional consultations was quantified; the type of health profession and the length of the visit were specified. The use of prescribed medication was determined including the type of medication, and the retail price. The number of days of hospital care and emergency department visits each with an overnight stay were quantified and the reason for admission specified. All four items (consultation, medication, hospitalisation, and productivity costs) were adapted from a third assessment tool, aside from the CATS and CAS, the Resource Utilization in Dementia Instrument (RUD) (Wimo & Nordberg, 2007). These expenses were covered by adding four additional questions to the original CATS and CAS.

The RUD is a structured interview capturing caregiver time, caregiver and patient direct medical resource utilisation and patient direct nonmedical resource utilisation. Caregiver productivity losses can also be assessed. In comparison with observational data the RUD based interview has proven to be a valid and reliable substitute (Wimo & Nordberg, 2007). In the same article, before conducting the actual validity and reliability assessment of the RUD, the authors described the validation of CATS, CAS and RUD up to this point as unsatisfactory (Wimo & Nordberg, 2007). Only very recently Neubauer and colleagues (Neubauer, Holle, Menn, & Gräbel, 2009) adapted a German version of the RUD and found it to be a valid instrument for measuring informal care time

for PWD. Nevertheless, both studies regarding the validity of the RUD were not published in time to be taken into consideration for the development of this study's design. Therefore, a mix of all three instruments seemed a sensible option when this study was designed by the author in 2007. For simplification, the adaptation of CAS, CATS and RUD was called 'Service Use Questionnaire'.

4.10.3.1 Gross costing method using a diary

The caregivers were provided with a diary to record the amount and type of intervention which they and the patients received during the forthcoming year – starting at baseline for the duration of 12 months.

The caregivers were asked to keep a record of the PWD's and their own use of healthcare services (consultation, hospitalisation, medication) and of the PWD's and their own use of support services (one-to-one counselling, group meetings). In addition, caregivers were also asked to record their own productivity costs (days of work loss due to care).

The majority of direct cost items assessed using the diary, were also assessed with the questionnaire at baseline and follow-up interview: consultation, medication, hospitalisation, and productivity costs. Since there was no experience using diaries over 12-months duration in dementia, a certain risk of diaries not being returned or being filled in incorrectly was anticipated. The author therefore wanted to obtain at least some of the costs assessed using both methods to prevent missing data.

The Service Use Questionnaire limited the number of costs that had to be recorded in the service use and costs diary. It was hoped that informants might feel more motivated to complete and return the diaries by the end of the study. So far only a couple of studies, conducted on expenditures related to caring for patients with dementia at home by using diaries, are known to the author. One study protocol has been published by Jansen and colleagues (Jansen, et al., 2005). They reported the use of diaries to measure direct and indirect costs of PWDs and their caregivers, but no results have been published yet. In another study, Weinberger and colleagues asked the

primary caregivers to keep a service use diary for six months (Weinberger, et al., 1993). The return rate was an acceptable 53.4%. More recent studies found the diary method to be an instrument which can successfully answer cost-effectiveness questions in long-term trials with completion rates of 68% (Goossens, Rutten-van Molken, Vlaeyen, & van der Linden, 2000), 83% (van den Brink, et al., 2005), and 87% (Goldfeld, Wright, & Oberklaid, 2003) after using diaries for 1 year. Instead of using the Service Use Questionnaire, all direct and indirect costs could have been measured using only diaries. Although using healthcare diaries is a viable methodology (Freer, 1980; Verbrugge, 1980), the number of items required to be recorded each week could have overburdened caregivers and led to a lower return rate than using the methodology described here. Using different methods on selected items was on the one hand a compromise with regards to the co-operation required from caregivers. On the other hand, this mixed-method approach allowed data to be validated in three different ways.

The service use and costs diary in Appendix L (p. 399) was developed by the author as a folder, containing instructions, an example (one completed week-sheet), a telephone number to dial in case of questions, and an accompanying information leaflet explaining the objectives of the diary. Each diary covered a period of 12 months, containing 52 week-sheets where each sheet represented 1 week. Caregivers received one diary covering the entire year but were then asked to mail a set of four week-sheets by the end of each month to the author. In this way numbers were continuously entered into the database while the trial was still running and emerging problems could be solved quickly. Also, if the diaries were not posted, the caregivers were called with a polite request to return them as soon as possible, maximising the return rate.

During the interview at baseline, caregivers received oral instruction to fill in the diary at least once per week or whenever they used one of the services included in the diary. The instruction was repeated in written form in each diary. The completed diaries were discussed with the caregivers during the follow-up interview to minimise partial responses and missing data. The caregivers were also asked to bring receipts and packaging, if available, from any medication

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purchased and receipts of other expenditures to cross-check the information recorded in the diaries.

4.10.3.2 TeleMessenger: automated reminder phone call

Carers were automatically reminded to fill in their diaries once per month for the duration of 1 year. Instead of making personal phone calls, the reminder system of 'TeleMessenger' software was used for this purpose.³² This meant a considerable amount of time savings. The software was also used as an answer machine so family-caregivers could leave messages for the author (problem, questions). These messages were collected by TeleMessenger and sent via e-mail to the author. TeleMessenger needed the following data: name of the family-caregiver, landline phone number of this caregiver (no matter if living with patient or not), and best time and day of the week to call him or her. It was crucial to reach the family-caregiver (or another person of the household who has been informed and is able to take notes) but not the PWD, since it might have been difficult for the PWD to pass on the message. The family-caregivers were asked to identify themselves ("Please press 1 if you are Mr./ Mrs. X, please press 2 if you are not Mr./ Mrs. X"). The following scenarios were possible:

1. The family-caregiver answered the phone (=1); he/she was reminded and could leave a message;
2. Nobody answered the phone but an answer machine recorded the reminder notice;
3. Nobody answered the phone and there was no answer machine to record the notice = *error*
4. somebody else (patient, other family member) answered the phone (=2) = *error*
5. if none of the above options happened = *error*

³² 'TeleMessenger' is a software company in Christchurch (TeleMessenger Solutions Limited, 33 Sir William Pickering Drive, Canterbury Technology Park). Contact person is Gary Rountree, manager of 'TeleMessenger', who supports the study by providing the software, recording electronically information from the study participants, and delivering this information to the author via e-mail.

The reminder call was usually made on the last Friday of each month. During the following couple of days the researcher logged into the TeleMessenger database to check for *error* messages in which case she rang the family-caregiver personally. Participants were informed about the reminder system by the researcher in written and oral form during the first interview at baseline and during a personal phone call approximately 4 weeks after baseline. Data required by TeleMessenger to set up the software were collected during the first interview and forwarded to TeleMessenger immediately. Participants were also asked to inform the author about a longer time of absence (such as holidays) so the calls could be stopped for this period of time.

4.10.3.3 Survey on TeleMessenger technology

Using automated phone calls, caregivers had been reminded to send in the diary sheets by the end of each of the 12 months. This technology had been kindly provided by TeleMessenger, a Christchurch based telecommunication company. Data were collected anonymously from caregivers who had completed the follow-up assessment and those who discontinued the study because the PWD had moved into permanent care ($n = 45$). The survey was filled in by the majority of caregivers ($n = 28$, 65.1%). Most of these caregivers (85.7%) were older than 55 years of age. The remaining 15.3% were aged between 46 and 55 years. Almost all (but two) respondents were women (92.9%). The majority of surveyed participants owned a cell phone (60.7%). **Table 15** shows that the majority of caregivers found the automated call to be very effective or even extremely effective in reminding them to send in the diary sheets. Two thirds of respondents thought that the automated call was as effective as a real person calling. The other respondents were about evenly split between considering the call as less effective than a real person calling or as more effective. The table also indicates that the majority of caregivers (57.1%) had no preference when given the choice between an automated call and a real person calling to remind them of the diaries. Almost all respondents (87.5%) had no problem with the computer voice of the automated call and thought it was quite clear, pleasant and easy to understand.

However, a minority felt very different about the voice. Some of the negative comments were: “hilarious, too unrealistic, American accent” or “I got confused and started talking to it”. Most people (88.5%) also did not feel that the calls became tiresome in any way. Again, some respondents were less satisfied with the call and commented as following: “Yes (it did become tiresome), to the point the reminder was ignored by hanging up.”; “stressed by too many phone calls”. The majority (80%) of those respondents who owned a cell phone did not believe that a short text message (SMS) would be more effective (**Table 15**).

Table 15: Outcomes of TeleMessenger survey at follow-up

Percentage of caregivers (n = 28)	
<i>Effectiveness of call as a reminder to send diary sheets</i>	
Totally ineffective	7.4%
Slightly ineffective	3.7%
Effective	37.0%
Very effective	33.0%
Extremely effective	18.5%
<i>Effectiveness of call as a reminder compared to real person</i>	
A lot less effective	3.7%
Slightly less effective	11.1%
About the same	66.7%
Slightly more effective	7.4%
A lot more effective	11.1%
<i>Choice between automated reminder call or a real person calling</i>	
Automated call	21.4%
Real person	21.4%
No preference	57.1%
<i>Computer voice</i>	
good	87.5%
not so good	12.5%
<i>Calls became tiresome</i>	
yes	11.5%
no	88.5%
<i>SMS would be more effective than call*</i>	
yes	20.0%
no	80.0%

*question applied only to cell phone owners (n = 15)

Overall, the results of this short survey show that the automated phone call was well accepted amongst respondents as a good alternative to a real person calling them. This means such

technology could be successfully used as a cheap, time saving option in research as well as in real life situations like reminder calls for doctor appointments.

4.10.3.4 Validation of data on direct costs through Nurse Maude Services

In addition to the Service Use Questionnaire and the diary, a third method was used to obtain care utilisation data. Out of the sample group a sub-sample group was built that consisted of participants who were using services of the Nurse Maude Association. Since Nurse Maude Association is the biggest service provider for age related homecare in Canterbury, there was a high probability that participants of this study were using Nurse Maude's service if they used any homecare services at all. Data regarding patients' in-home care utilisation provided by the caregivers during the baseline and follow-up assessments were confirmed with data provided by Nurse Maude Association after the follow-up interview for those Nurse Maude clients who were also participating in this study.

4.10.4 Perceived economic burden: Cost of Care Index - part 5 (CCI)

After analysing this study's baseline data, a new aspect emerged which had not been considered at the beginning of the study when the design and methodology were set up. The topic could be best described as "perceived individual economic burden" as opposed to the societal economic burden. Data generated from the following items supported this theory:

- Joint pension or income (part of the socio-demographic questionnaire)
- Item 12 of the QOL-AD questionnaire: "How do you feel about your current situation with money, your financial situation? Do you feel it's poor, fair, good, or excellent?"
- Item 15 of the Zarit BI: "Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses? How often do you feel this way: never; rarely; sometimes; quite frequently; nearly always?"
- Item 23 of the GDS: "Do you think that most people are better off than you are? YES / NO"

It was therefore decided that at follow-up the fifth part of the Cost of Care Index (CCI)³³ should be included in the interview process (Appendix M, p. 416). The CCI was developed by Kosberg and Cairl (1986) as a case management tool to identify problems of family-caregivers who take care of an elderly relative. This 20-item instrument provides measures of subjective burden in five domains one of which is related to economic costs. This domain consists of four statements including, for example, "I feel that my family and I must give up necessities because of the expense to care for my elderly relative.", and caregivers can either "strongly agree", "agree", "disagree" or "strongly disagree" generating between 1 and 4 points with an overall score between 4 and 16. Higher scores indicate higher levels of economic burden. The CCI has been shown to be valid and reliable (Kosberg, Cairl, & Keller, 1990).

In addition to the CCI-part 5, the following question was also included in the "Economic Questionnaire": "Do you think financial assistance would help you to fulfil your role as a caregiver (enabling your relative to live at home as long as possible)". This question could be answered either with "yes" or "no" (Appendix M, p. 416).

The Economic Questionnaire also included one question on the utilisation and costs of participants' dementia- or mental health drugs (Appendix M, p. 416).

4.11 Qualitative data

Since in New Zealand barely any research has been conducted on dementia and since even some of the more basic statistical information for the population concerned are missing (Access Economics, 2008) the design of this study was agreed to be mainly quantitative. However, a mixed method approach is widely regarded as the gold standard of research (Meline, 2006). Consequently, it was decided to obtain also some qualitative data, but with a very specific and limited focus, in order to remain within the time and personnel constraints of this study.

³³ In later publications, such as Kosberg, Kaufman, Burgio, Leeper, & Sun (2007), this questionnaire is referred to as Consequences of Care Index (CCI).

Qualitative data were collected from all participants through one-to-one semi-structured interviews. The main focus of these interviews was participants' service utilisation. During the baseline interview PWD and caregivers were asked the following questions:

- What is it that helps you the most at the moment?
- What is most important for you at the moment?
- Is there something you are worried about?

Since the baseline interview took place only shortly after a diagnosis had been made, the author did not anticipate a wide variety of services being utilised at this point. However, this semi-structured interview was also an opportunity for participants to express their point of view relating to the diagnosis, as well as participants' coping mechanisms and support strategies. The qualitative data therefore not only provided important information on service utilisation but also enabled the researcher to identify important aspects that might have impacted participants' QoL at the time, without that such aspects might have been revealed during the first (quantitative) interview part.

It was expected that formal supports would become increasingly important with time and illness progression and the researcher hypothesised that this increased care need would be reflected during follow-up interviews during which the following questions were directed at both PWDs and caregivers:

- How has the past year been for you especially in regards to your (relative's) memory? Do you feel it has remained about the same or did get worse?
or
- I can imagine that the past year hasn't been easy sometimes. Can you tell me more about it?
- What was/is it that helped you the most to cope? Can you give me an example?
or
- What was most important for you in the past year? Can you give me an example?

- Regarding your (relative's) illness/ memory, is there something you are worried about?
- Why did you decide not to attend any group meetings/day care/Alzheimers Canterbury?
(if applicable)

The questions aimed again at service utilisation with a special focus on reasons for participants not to take advantage of a certain allocated formal service like day care (if applicable). It was anticipated that this data could help to improve the quality of services and to make recommendations for an efficient service allocation.

Qualitative data were usually collected at the end of each participant's interview process. However, if participants indicated a need to talk about certain aspect of their lives relating to their or their relative's illness which clearly answered the qualitative questions to be asked later the order of the interview could be readjusted accordingly. Semi-structured interviews ranged from 1 to 20 minutes with an average of 10 minutes length per participant.

4.12 Analysis

4.12.1 Statistical analysis of clinical measures

The study design included the collection of a wide variety of quantitative data through the completion of several questionnaires as outlined in sections 4.7 and 4.8, administered by the author at baseline and at 12-months follow-up. The data obtained from these questionnaires were analysed using a number of different statistical methods. Descriptive statistics included analyses of distributions, central tendencies and variability of the study population by calculating for example mean, variance and standard deviation. Inferential and multivariate statistics were used to examine differences between baseline and follow-up data as well as to identify relationships (and their strength) between two or more variables. The following methods were used: Pearson's correlation, (stepwise) multiple regression analysis, one-way ANOVA and two-way ANOVA. Graphical representations of relationships identified were performed, for example scatter plots and bar charts.

4.12.2 Gross costing analysis of costs

As outlined in section 4.10.1 (p. 147) costs in this study were estimated using the **gross costing method** in which the utilisation of important types of care are summed and then multiplied by a unit cost for each type of care. This method allowed identifying direct and indirect dementia related costs, measuring the out-of-pocket-expenses and productivity costs for the duration of 1 year. Rather than analysing costs for each of the 12 months separately data were split into 3-month intervals resulting in a quarterly mode.

4.12.3 Qualitative data

As explained earlier (section 4.11, p. 161), the qualitative data in this study were collected to enrich the otherwise purely quantitative contents. It was not the researcher's intention to create a theoretical model or framework of coping in dementia or QoL in dementia, but to simply give participants their own voice and fill gaps of knowledge that might have otherwise be left undetected by the exclusive use of questionnaires.

Unfortunately, due to time constrains, this data could not be analysed within the timeframe of the thesis. It was agreed between the researcher and her supervisors to analyse the semi-structured interviews for a publication to be written after this thesis was completed.

5 Results

The first part of this chapter outlines the baseline findings of the prospective cohort study. The results of the follow-up data analysis are shown in the second part (p. 209), followed by an examination of participants lost to follow-up (p. 227). Finally, the results of the formal care analysis (p. 230) and economic evaluation are presented (p. 275). A summary concludes this section (p. 309). The outcomes presented in this chapter are preceded by an overview of the representativeness of the study sample as well as by calculations of the return rate of the service use and cost diaries (p. 168).

5.1 Representativeness of study sample

During the enrolment period between September 2007 and August 2008, the primary investigator contacted 78 family-caregivers of PWDs. Fifty-three PWDs and their caregivers ($n = 53$ dyads) agreed to participate in the study and 25 declined, which equals a response rate of 67.9%. At the beginning of the data collection, the researcher had been reassured by the memory clinic staff that the recruitment of 100 dyads within 12 months was a realistic goal. However, at the time, the memory clinic had only operated for about 1 year and therefore their ability to predict recruitment rates might have been somewhat limited³⁴.

The majority of participants (83.0%) were from Christchurch, whereas 17.0% lived in rural Canterbury including smaller towns such as Ashburton and Amberley. The Census data from 2006 show that there were 521,832 people living in Canterbury (Statistics New Zealand, 2006b). Of those, 348,435 (66.8%) lived in Christchurch (Statistics New Zealand, 2006a). These numbers show that participants from the urban centre of Christchurch were overrepresented and participants from the more rural areas of Canterbury underrepresented.

³⁴ Please refer to the section 5 “Recruitment of participants” of the previous chapter (p. 143) for more information.

The analysis of the socio-demographic data as well as the analysis of the clinical data indicates a relatively high representativeness of the study sample which included persons with different dementias at different stages of illness. Participants were also spread across a wide range of socio-economic backgrounds. However, limited numbers mean that the results can be more easily generalised for Canterbury and Christchurch in particular than for New Zealand. Representativeness is also slightly limited since 83% of patients enrolled had mild dementia, 15% moderate and 2% severe dementia. The table below shows that the nationwide numbers were estimated at 55% mild dementia, 30% moderate and 15% severe dementia (Access Economics, 2008). In comparison, these nationwide estimates were spread more evenly across the different stages of dementia than in this study. However, before the inclusion criteria were changed, only patients with mild to moderate dementia were recruited for this study. The skewness towards mild and moderate dementia and away from severe dementia was therefore not unexpected.

Table 16: Comparison of dementia severity in this study and nationwide (percentage)

Stage of dementia	CDR score	Nationwide (%)	Study sample (%)
Very mild – mild	0.5 – 1	55	83
Moderate	2	30	15
Severe	3	15	2

Note. CDR, Clinical Dementia Rating Scale.

There were 521,832 people living in Canterbury (Statistics New Zealand, 2006b). It is estimated that 1% of the New Zealand population has dementia (Access Economics, 2008) which means that there were an estimated 5,218 PWDs in Canterbury in 2006.

As shown above, the majority of PWDs (55%) are believed to have an early stage dementia, 30% of PWDs are probably at a moderate stage and an expected 15% of patients have severe dementia (Access Economics, 2008). The following table presents the results of applying these percentages to PWDs in Canterbury.

Table 17: PWDs in Canterbury according to dementia severity (number, percentage)

Stage of dementia	CDR score	Canterbury	% of all PWDs
Very mild – mild	0.5 – 1	2,870	55%
Moderate	2	1,565	30%
Severe	3	783	15%
Total		5,218	100%

Note. CDR, Clinical Dementia Rating Scale.

Recently published data estimated that 50.0% of patients with early dementia, 46.8% with moderate dementia and 15% of patients with severe dementia are cared for at home (Access Economics, 2008). It can be calculated that in Canterbury, approximately 1,435 persons with mild dementia, 732 with moderate dementia and 361 with severe dementia were cared for at home during the time this study was conducted (Table 18). Of these 2,528 family-caregivers in Canterbury 53 (2.1%) participated in this study.

Table 18: PWDs cared for at home in this study, nationwide and in Canterbury by severity (number, percentage)

	Nationwide		Canterbury		Study sample	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%*
Mild	11,240	50.0	1,435	50.0	44	100.0
Moderate	5,699	46.8	732	46.8	8	100.0
Severe	2,807	46.1	361	46.1	1	100.0
Total	19,746		2,528		53	

Note. Nationwide numbers adopted from the 'Economic impact of dementia in New Zealand' report (Access Economics, 2008). Regional numbers were calculated based on nationwide numbers. (*) percentage of PWDs living at home as compared to living in residential care within a certain severity range.

5.2 Return rate of service utilisation and cost diaries

The total return rate across the entire year was 78.4 % which was calculated as following:

- 53 caregivers x 12 months = 636 months
 - less 146 months from discontinuing participants = 490 months
 - less 106 months not returned = 384 months (78.4%) total received.

A return rate of nearly 80% for a study period of 12 months is excellent. In comparison, Weinberger et al. (Weinberger, et al., 1993) utilised diaries in a dementia study over 6 months resulting in a return rate of 53.4%. Other studies also found the diary method to be an instrument, which can successfully answer cost-effectiveness questions in long-term trials with completion rates of 68% (Goossens, et al., 2000), 83% (van den Brink, et al., 2005), and 87% (Goldfeld, et al., 2003) after using diaries for 1 year. However, none of these long-term studies were conducted in cohorts of PWDs.

During the first quartile the resource utilisation assessment was based on data provided by 42 caregivers, which equals a return rate of 87.5 %. The second quartile calculations were based on monthly diary data provided by 34 caregivers, resulting in a return rate of 85.0%. The third quartile still generated data from 26 caregivers with a return rate of 72.2%. During the last 3 months 20 participants provided diary data for analysis, which equals a return rate of 60.6%. Discontinuing participants were considered for the calculation of all return rates.

Diary data were excluded from the analysis if either the participant discontinued the study at the third, sixth, ninth or twelfth month or the weekly diary sheets had not been returned to the author more than once (out of three times) within one quartile.

5.3 Prospective cohort study: baseline

This section presents the outcomes of the data collected at baseline. First, the socio-demographic data were analysed. Second, factors predicting patients' QoL were evaluated (p. 174). Finally, predictors of caregivers' QoL were analysed (p. 199).

5.3.1 Socio-demographic characteristics

The socio-demographic characteristics of participants were assessed at the beginning of the data collection process (baseline), and are detailed in the following paragraph.

- Interviews were conducted with 53 PWDs and their 53 informal caregivers (106 participants in total) of whom 79.2% lived in the same household. Thirty-one men (58.5%) and 22 women with dementia and their family-caregivers were included.
- PWDs' average age was 77.7 years with the youngest patient being 57 and the oldest 89. One in two PWDs (50.9%) was older than 80 years of age.
- The majority of caregivers, 42 (almost 80%), were women, as compared to only 11 men.
- Forty-one percent (41.5%) of caregivers were younger than 65 years of age. Caregivers were aged between 34 and 90 years with a mean age of 67.8 years.
- The majority of participants (90.6%) were New Zealanders. One person (1.9% of the PWDs) was Maori. Some participants considered themselves as being Scottish or Irish even though they were New Zealand residents and had lived in New Zealand for several decades.
- Most caregivers were patients' spouses (67.9%) or children (20.8%). The other caregivers were either friends or siblings of the PWD.
- Almost 90% of caregivers, but only about every second patient (56.6%), had continued education after attaining the minimum school leaving age.

- Half of the caregivers (49.1%) and two thirds of the PWDs (67.9%) did not hold a University level degree or equivalent professional qualification.
- Close to 40% of caregivers were in paid employment at the time of the baseline interview. Of these caregivers, there were six (28.6%) who could not work for up to 6 days within the two week prior to the interview because of their caregiving responsibilities.
- Most participants (45.3%) fell into the lowest of three income categories, having a joint income/pension of less than NZ \$25,000 per year.
- Most participants held a community services card. Still, 1 in 5 (22.6%) PWDs and 41.5% of caregivers did not hold a community services card. One-way ANOVA showed no significant differences between PWDs being card holders and those who did not have a community services card regarding their medical service utilisation. However, some differences were observed for caregivers (5.7.2, p. 233).

The study's socio-demographic findings are collated in **Table 19** on the following page.

Table 19: Participants' socio-demographic and economic characteristics

Patients (<i>n</i> = 53)				Caregivers (<i>n</i> = 53)			
		<i>n</i>	%			<i>n</i>	%
Living in shared household	Yes	42	79.2	Living in shared household	Yes	42	79.2
	No	11	20.8		No	11	20.8
Age (years)	< 65	2	3.8	Age (years)	< 65	22	41.5
	65 – 80	24	45.3		65 – 80	21	39.6
	> 80	27	50.9		> 80	10	18.9
Gender	Female	22	41.5	Gender	Female	42	79.2
	Male	31	58.5		Male	11	20.8
Ethnicity	NZ European	48	90.6	Ethnicity	NZ European	48	90.6
	Maori	1	1.9		Maori	0	0.0
	Other	4	7.5		Other	5	9.4
Relationship with caregiver	Spouse	36	67.9	Relationship with patient	Spouse	36	67.9
	Parent	11	20.8		Child	11	20.8
	Other	6	11.3		Other	6	11.3
Secondary education	Yes	30	56.6	Secondary education	Yes	47	88.7
	No	23	43.4		No	6	11.3

Table 19: Socio-demographic characteristics of participants at baseline (continued)

Patients (<i>n</i> = 53)				Caregivers (<i>n</i> = 53)			
		<i>n</i>	%			<i>n</i>	%
Degree/Qualification	Yes	17	32.1	Degree/Qualification	Yes	27	50.9
	No	36	67.9		No	26	49.1
Being in paid employment	n. a.			Being in paid employment	Yes	21	39.6
					No	32	60.4
Days of work loss during 2 weeks prior to baseline interview	n. a.			Days of work loss during 2 weeks prior to baseline interview	0	15	71.4
					1	4	19.0
					2	1	4.8
					6	1	4.8
Joint income/pension	n. a.			Joint income/pension of patient and caregiver per annum	NZ \$ < 25,000	24	45.3
					NZ \$25,000 - 50,000	17	32.1
					NZ \$ > 50,000	12	22.6
Community Services Card holder	Yes	41	77.4	Community Services Card holder	Yes	31	58.5
	No	12	22.6		No	22	41.5

A one-way ANOVA analysis was performed regarding possible differences between the three categories of relationship between PWDs and their caregivers. It was found that children and friends looked after PWDs who are more cognitively ($r = -.441, p = .001$) and functionally impaired ($r = .320, p = .020$), than PWDs looked after by their spouses. Being looked after by a daughter, son or friend might be an indicator for an increased functional and cognitive impairment. It was further determined that 2 out of 3 children did not live together with their parents with dementia whereas 1 out of 3 did live with their parent.

Caregivers' age or gender did not predict their QoL. **The hypothesis listed under point 1.b of chapter 3.3 (p. 114) that caregivers' QoL might be impacted by being female was not supported.** However, PWDs' age was negatively correlated with their depression levels ($r = -.274, p = .047$) and caregivers' distress ($r = -.314, p = .022$) and depression scores ($r = -.309, p = .025$), indicating that younger PWDs were more likely to have depressive symptoms or be depressed and their caregivers were more distressed and also more depressed.

PWDs' gender was strongly positively correlated with the stage of dementia ($r = .361, p = .008$), the relationship to the caregiver ($r = .471, p < .001$) and the living arrangements ($r = .607, p < .001$). This means that women with dementia were at a later stage of illness and more likely to be looked after by their children or friends (rather than spouses) with whom they would often live together.

Interestingly, there was also a significant correlation between PWDs' gender and age ($r = .311, p = .024$). These results taken together indicate that women with dementia in this study not only tended to be at a later stage of illness but they were also older than men with dementia. These findings were confirmed using a one-way ANOVA analysis. Table 20 shows that there were more men than women with dementia and these men were on average 4.5 years younger than the women with dementia. Interestingly, the table also shows that the opposite was true for caregivers in this study: caregivers were mainly female and on average almost 10 years (9.6) younger than men.

Table 20: One-way-ANOVA: differences between male and female participants' regarding their mean age

<i>n</i>		Mean ± Standard error of the mean (SE)	<i>F</i> _{1,50}	<i>p</i>
<i>PWDs</i>				
Men	31	75.7 ± 1.37	4.85	.032
Women	21	80.2 ± 1.48		
<i>Caregivers</i>				
Men	11	75.6 ± 3.76	5.86	.019
Women	41	66.0 ± 1.77		

Key. PWDs, persons with dementia

Based on these findings it can be concluded that women with dementia in this study were most likely to be looked after by children, or by a brother or sister, whereas men with dementia were most likely to be looked after by their spouse.

5.3.2 Clinical measures of patient quality of life

The following results relate to the hypotheses (as listed under point 1.a of chapter 3.3, p. 114).

The measures were first analysed in a descriptive way, followed by an evaluation of their quality as predictors of PWDs' QoL (mainly Pearson's correlation).

Table 21 represents patients' clinical characteristics based on the total sample of 53 as well as in relation to patients' pathology of dementia.

Table 21: PWDs' mean clinical scores at baseline for total sample and according to pathology and significance values for differences between pathologies

	Mean \pm SE [Range: minimum – maximum]				$F_{2,50}$	p
	Total sample $n = 53$	Alzheimer's dementia $n = 31$	Vascular dementia $n = 14$	Mixed dementia $n = 8$		
CDR	1.0 \pm 0.1 [0.5 – 3]	0.8 \pm 0.1 [0.5 – 2]	1.2 \pm 0.2 [0.5 – 2]	1.6 \pm 0.3 [1 – 3]	11.10	.000
3MS ($n = 52$)	71.1 \pm 1.5 [49 – 91]	71.4 \pm 2.2 [49 – 91]	70.9 \pm 2.6 [57 – 86]	70.5 \pm 3.7 [56 – 82]	0.08	.928
QOL-ADp	38.0 \pm 0.8 [19 – 47]	40.1 \pm 0.7 [31 – 47]	36.2 \pm 2.1 [19 – 47]	33.3 \pm 1.6 [26 – 40]	6.39	.003
QOL-ADproxy	34.8 \pm 0.8 [17 – 47]	36.7 \pm 0.9 [22 – 47]	32.1 \pm 1.7 [17 – 42]	32.6 \pm 2.0 [26 – 40]	3.89	.027
CSDD	6.3 \pm 0.6 [0 – 22]	5.0 \pm 0.4 [0 – 10]	7.3 \pm 1.3 [3 – 22]	9.6 \pm 2.1 [3 – 22]	5.40	.008
NPI	10.1 \pm 1.4 [0 – 57]	7.2 \pm 1.2 [0 – 22]	12.9 \pm 2.8 [0 – 32]	16.0 \pm 6.1 [3 – 57]	3.28	.046
BADLS	8.5 \pm 1.0 [0 – 32]	6.3 \pm 1.1 [0 – 25]	12.8 \pm 2.5 [0 – 32]	9.8 \pm 1.7 [3 – 16]	4.16	.021
Comorbidities p	9.8 \pm 0.9 [0 – 31]	9.2 \pm 1.2 [0 – 28]	10.6 \pm 2.2 [0 – 31]	11.3 \pm 1.7 [4 – 18]	0.386	.681
Comorbidities proxy	13.5 \pm 1.2 [2 – 38]	10.9 \pm 1.1 [2 – 26]	18.3 \pm 2.8 [4 – 38]	15.1 \pm 3.0 [5 – 31]	4.46	.017

Key. PWDs', persons' with dementia; CDR, Clinical Dementia Rating Scale; 3MS, Modified Mini-Mental State Examination; QOL-ADp, Quality of Life-Alzheimer's Disease Scale patient rating; QOL-ADproxy, Quality of Life-Alzheimer's Disease Scale proxy rating; CSDD, Cornell Scale for Depression in Dementia; NPI, Neuropsychiatric Inventory; BADLS, Bristol Activities of Daily Living Scale; Comorbidities p, patients' health status patient ratings; Comorbidities proxy, patients' health status proxy ratings.

5.3.2.1 Pathology

The results below relate to the following hypothesis: PWD's QoL may be predicted by the type of dementia (as listed under point 1.a of chapter 3.3, p. 114).

The majority of patients (58.5%) was diagnosed with AD, followed by 14 persons (26.4%) diagnosed with VD and 8 participants (15.1%) with mixed dementia as **Figure 6** illustrates.

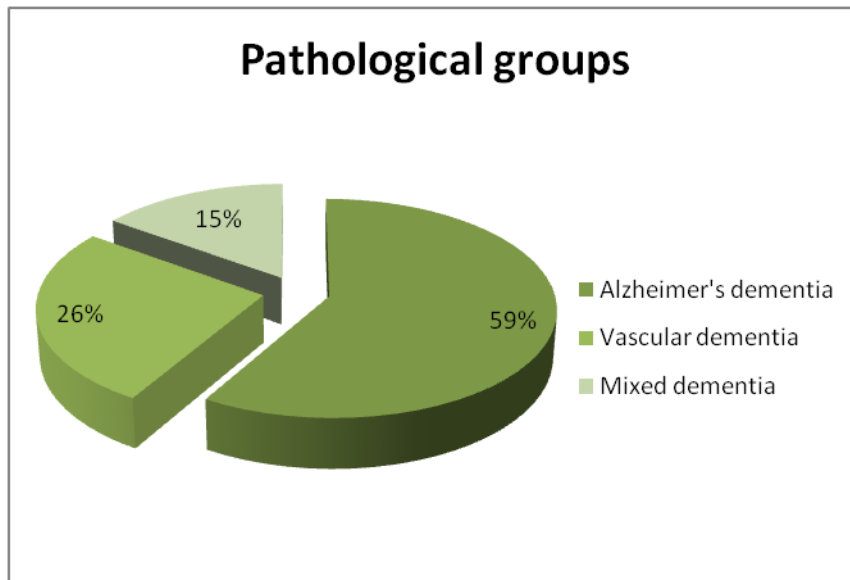


Figure 6: Pathological groups at baseline (percentage)

The type of dementia was strongly related to a number of outcomes:

- the stage of dementia ($r = .546, p < .001$),
- PWDs' QoL: patient ratings ($r = -.435, p = .001$),
- PWDs' depressive symptoms ($r = .414, p = .002$).

Some further correlations were also found with the following outcomes:

- PWDs' QoL: proxy ratings ($r = -.278, p = .044$),
- neuropsychiatric and behavioural symptoms ($r = .320, p = .020$),
- caregivers' depressive symptoms ($r = -.274, p = .048$).

These correlations show that participants with AD were more likely to be at an earlier stage of dementia, rate their QoL higher and be less depressed than participants with VD or mixed dementia. There was also some indication that persons with AD received higher proxy ratings of

their QoL from their caregivers, that participants with AD had fewer and less severe neuropsychiatric and behavioural symptoms and that their caregivers were less depressed than caregivers of participants with VD or mixed dementia.

Using a one-way ANOVA analysis, the same outcomes were also found to be the ones for which the most significant differences between the AD group and the other two diagnostic groups were observed (stage of dementia: $p < .001$, PWDs' QoL patient rating: $p = .003$; depression: $p = .008$). Interestingly, no such differences were found for caregiver outcomes.

Figure 7 shows that PWDs' QoL was rated higher by both, patients and caregivers, if patients had been diagnosed with AD as compared to VD and mixed dementia. The difference between pathological groups was statistically significant at the $p < .01$ level for patients' QOL-AD ratings ($F_{2,50} = 6.39, p = .003$); and at the $p < .05$ level for caregivers' proxy ratings ($F_{2,50} = 3.89, p = .027$). AD patients' higher QoL scores might be explained by the fact that persons with vascular and mixed dementia had on average higher depression and NPI scores and were further advanced in their illness and more functionally impaired than AD patients (Table 21). **The hypothesis that PWD's QoL may be predicted by the type of dementia was supported with AD predicting better QoL than VD or mixed dementia.**

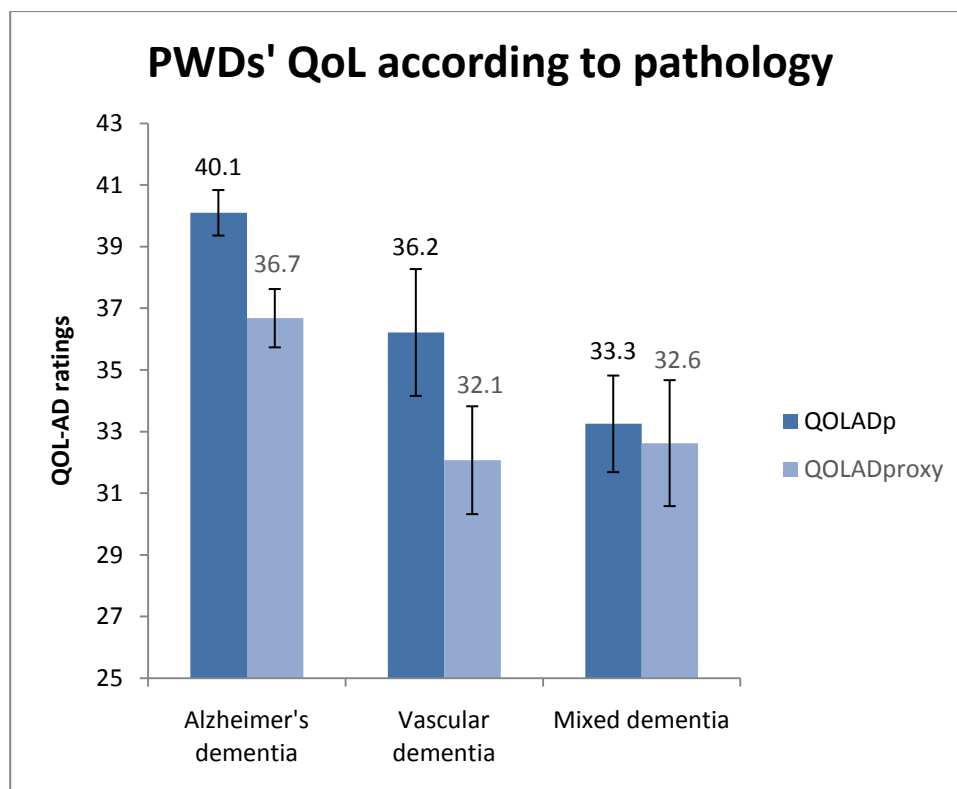


Figure 7: Differences between ratings of PWDs' QoL according to pathological groups

Key. PWDs', persons' with dementia; QoL, quality of life; QOL-ADp, Quality of Life-Alzheimer's Disease Scale patient rating; QOL-ADproxy, Quality of Life-Alzheimer's Disease Scale proxy rating.

Note. The difference between pathological groups was statistically significant: QOL-ADp ($F_{2,50} = 6.39, p = .003$); QOL-ADproxy ($F_{2,50} = 3.89, p = .027$).

5.3.2.2 Stage of dementia

The results in this section relate to the hypothesis that PWD's QoL may be predicted by the illness severity (as listed under point 1.a of chapter 3.3, p. 114).

The table below illustrates that the majority of patients (83%) were in the early stages of dementia. Only 17% of patients had already advanced to a moderate or severe stage. On average persons with mixed dementia were at a moderate stage of illness (1.6 out of 3 points on the CDR) and persons with VD and AD were at a mild stage (1.2/0.8 out of 3 points) as can be seen from Table 21 (p. 175).

Table 22: Severity of dementia at baseline

Stage of dementia	CDR score	<i>n</i>	%
Very mild	0.5	19	35.8
Mild	1	25	47.2
Moderate	2	8	15.1
Severe	3	1	1.9

Key. CDR, Clinical Dementia Rating Scale.

Pearson's correlation analysis showed the following strong correlations between the stage of dementia and:

- cognition ($r = -.360, p = .009$),
- PWDs' QoL: patient ratings ($r = -.615, p < .001$),
- PWDs' QoL: proxy ratings ($r = -.437, p = .001$),
- level of daily functioning ($r = .614, p < .001$),
- number of formal care contacts ($r = .486, p < .001$),
- length of formal care contacts ($r = .566, p < .001$),
- PWDs' health status: proxy ratings ($r = .402, p = .003$).

These correlations indicate that a more advanced stage of illness predicted significantly more impairment of patients' cognitive abilities, their QoL (patient and caregiver perspective) and daily functioning. Patients at a later stage of dementia received significantly more formal care during appointments which took longer compared to persons with mild dementia. **These results support the hypothesis that PWD's QoL may be predicted by the dementia severity with better QoL at an earlier stage of dementia.**

5.3.2.3 Cognition

The results in this section relate to the hypothesis that PWDs' QoL is not impacted on by level of cognitive impairment, as listed under point 1.a of chapter 3.3 (p. 114).

Table 23 shows that just over 1 in 3 PWDs (36.5%) scored more than 78 points, the cut-off level for no impairment, at baseline. About one-third of patients achieved between 68 and 77 points indicating a mild cognitive impairment. Almost one-third of patients (30.8%) scored between 38 and 67 points, which indicates a moderate level of cognitive impairment. What is interesting in this data is that, even though only 15.1% of patients were rated to have dementia at a moderate stage, more than 30% of PWDs were already moderately impaired in their cognition. This supports the fact that the level of cognitive impairment plays an important role in determining the stage of dementia a patient is in but it is not the same concept and cannot be a substitute for the illness progression.

Table 23: Severity of cognitive impairment at baseline

Severity of cognitive impairment	3MS score	<i>n</i> (<i>n</i> = 52)	%
None	≥ 78	19	36.5
Mild	68 – 77	17	32.7
Moderate	38 – 67	16	30.8
Severe	≤ 37	0	0.0

Key. 3MS, Modified Dementia Rating Scale.

Cognition was not significantly correlated with PWDs' or caregivers' QOL-AD ratings. But there was strong evidence that patients' cognitive abilities decreased with illness progression ($r = -.360$, $p = .009$) and more impaired daily functioning ($r = -.328$, $p = .018$), which was to be expected. **The hypothesis that PWDs' QoL is not impacted on by level of cognitive impairment was supported based on the results of this study.**

5.3.2.4 Quality of life: patient's perspective

The results of this section and of the following section (5.3.2.5, p. 185) relate to the following hypotheses as listed under point 1.a of chapter 3.3 (p. 114):

- PWDs' QoL is predicted by depression; neuropsychiatric and behavioural symptoms; daily functioning; their general health or comorbidities prevalent in addition to the dementia; and caregivers' burden and level of distress.
- PWD's QoL may be predicted by caregivers' QoL, support caregivers receive from family and friends; caregivers' health; and caregivers' perceived economic burden.
- PWDs' QoL is probably not influenced by caregivers' level of depression.

PWDs rated their own QoL as being impaired already at an early stage of illness. Persons with very mild dementia rated an average 40.9 out of a possible 52 points on the QOL-AD and persons with mild dementia 38.5 points. Mean scores decreased significantly with progressing illness ($F_{2,48} = 16.16, p < .001$) as can be seen from **Table 24**.

Table 24: One-way ANOVA: differences between patients' mean QoL ratings according to dementia severity at baseline

	Mean \pm SE [Range: minimum – maximum]				$F_{2,48}^*$	p
	Very mild $n = 19$	Mild $n = 25$	Moderate $n = 8$	Severe $n = 1$		
QOL-ADp	40.9 \pm 0.9 [33 – 47]	38.5 \pm 0.9 [26 – 47]	31.3 \pm 2.5 [19 – 42]	26.0 \pm - [-]	16.16	.001

Key. QOL-ADp, Quality of Life-Alzheimer's Disease Scale patient rating.

*The QoL ratings from the one person with severe dementia were excluded from this one-way ANOVA.

Figure 8 also illustrates the significant decrease of patients' average QoL ratings.

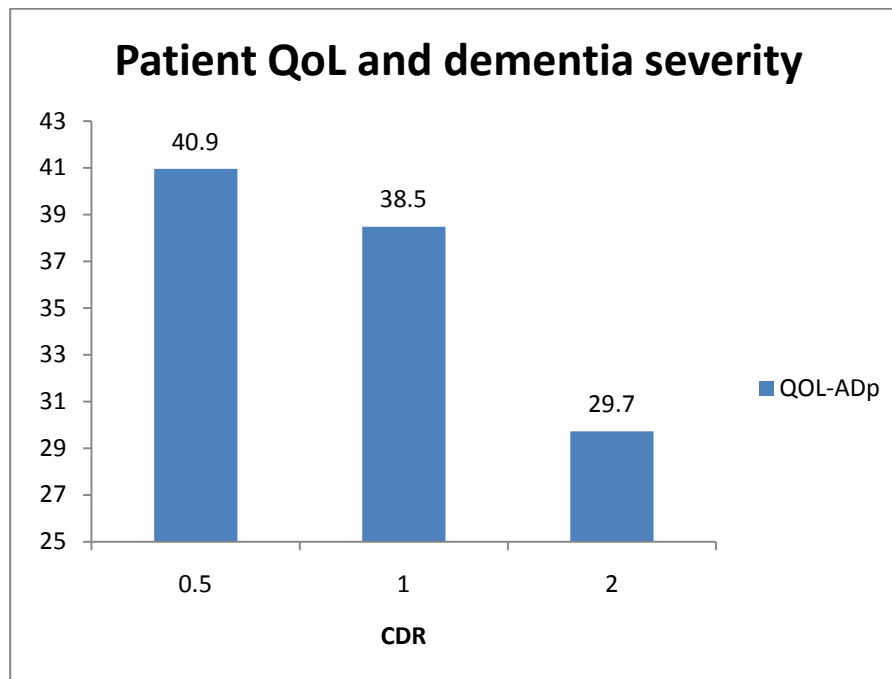


Figure 8: Patient QoL (mean QOL-ADp scores) according to dementia severity at baseline

Key. QoL, quality of life. QOL-ADp, Quality of Life-Alzheimer Disease Scale patient ratings; CDR, Clinical Dementia Rating Scale.

Most measurements were associated with PWDs' QoL. In detail, patient ratings of their own QoL were correlated significantly with:

- stage of illness ($r = -.615, p < .001$),
- PWDs' QoL: proxy ratings ($r = .688, p < .001$),
- PWDs' depressive symptoms ($r = -.415, p = .002$),
- neuropsychiatric and behavioural symptoms ($r = -.403, p = .003$),
- level of daily functioning ($r = -.546, p < .001$),
- PWDs' health status: proxy ratings ($r = -.471, p < .001$),
- caregivers' QoL ($r = .564, p < .001$) (Figure 9, p. 183),
- caregivers' level of burden ($r = -.480, p < .001$),
- caregivers' level of distress ($r = -.334, p < .015$),
- time spent on informal care ($r = -.374, p = .006$),
- caregivers' perceived economic burden ($r = -.481, p = .006$).

These results show that PWDs' QoL was predicted by a wide variety of factors. PWDs' QoL ratings were better if they were at an earlier stage of dementia; if caregivers rated patients' QoL and health status better; if patients' had fewer depressive, and neuropsychiatric and behavioural symptoms; if patients' were less functionally impaired; if caregivers were less (financially) burdened and distressed; and if caregivers spend less time on caring for the PWD. Caregivers' depression levels were not correlated with patients' QoL ratings.

The strong positive correlation between PWDs' QoL (QOL-ADp) and caregivers' QoL (QOL-ADc) was also reflected in a linear regression analysis ($R^2 = 0.318$) as **Figure 9** illustrates.

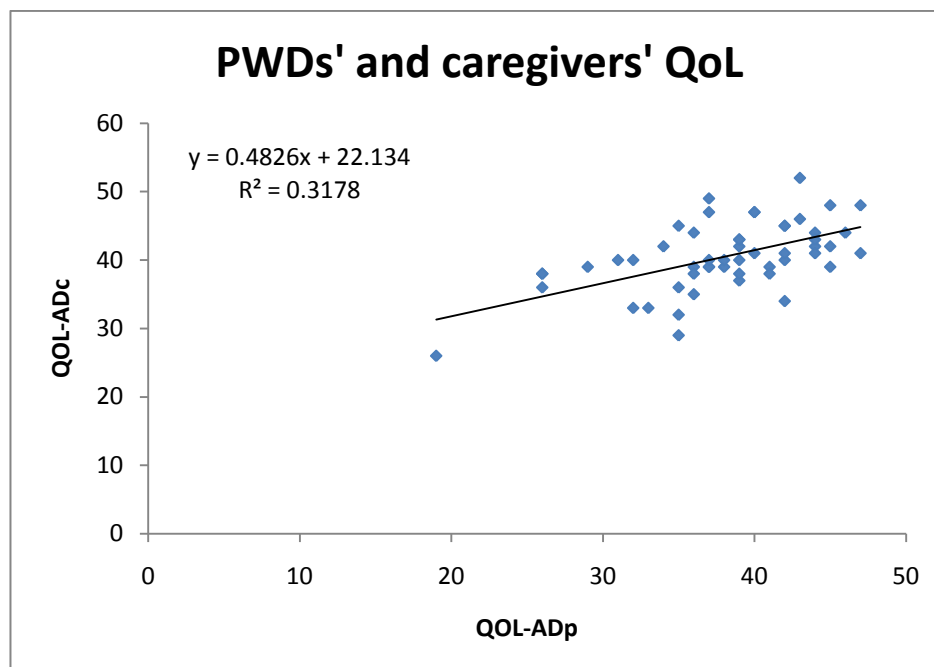


Figure 9: Linear regression between QOL-ADp and QOL-ADc ratings at baseline

Key. PWDs', persons' with dementia; QOL-ADp, Quality of Life-Alzheimer Disease Scale patient rating; QOL-ADc, Quality of Life-Alzheimer Disease Scale caregiver rating.

Stepwise linear regression analysis showed that PWDs' self rated QoL was best predicted by caregivers' QOL-AD proxy ratings, the stage of dementia and caregivers' health status (see **Table 25**). These three variables together explained 60% of the variance of patients' total QOL-ADp scores (adjusted $R^2 = .60$). This shows that the combination of all three factors was an important predictor for how PWDs rated their own QoL. Patients perceived their QoL as better if caregivers' proxy ratings were higher, the dementia was less advanced (CDR) and caregivers had a better health status (Comorbidities c).

Table 25: Summary of stepwise linear regression analysis for variables predicting PWDs' QoL (QOL-ADp)

	<i>B</i>	<i>SE B</i>
Step 1		
Constant	14.99	3.54
QOL-ADproxy	0.66	0.10***
Step 2		
Constant	24.59	4.03
QOL-ADproxy	0.50	0.10***
CDR	-3.96	1.04***
Step 3		
Constant	28.03	4.20
QOL-ADproxy	0.45	0.10***
CDR	-4.40	1.02***
Comorbidities caregiver	-0.14	0.07*

Key. QOL-AD proxy, Quality of Life-Alzheimer's Disease Scale proxy rating; CDR, Clinical Dementia Rating Scale; Comorbidities caregiver, caregivers' self rated health status; *B*, unstandardised regression coefficient; *SE B*, standard error of *B*.

Note. Adj. $R^2 = .45$ for Step 1; adj. $R^2 = .57$ for Step 2; adj. $R^2 = .60$ for Step 3 (** $p < .001$).

*** $p < .001$, * $p < .05$

In a different model, the researcher controlled for all caregiver outcomes and ratings and found that the stage of dementia alone explained 35.6% of the variance. In a second step it was observed that patients' health together with the stage of illness explained 40.3% of the variance of patients' total QOL-ADp scores.

In a third model, the researcher not only controlled for all caregiver ratings but also for patients' health status. In this model the stage of illness and patients neuropsychiatric and behavioural symptoms explained 39.8% of the variance of patients' total QOL-ADp scores.

Based on these results the following hypotheses were supported:

- PWDs' QoL is predicted by their level of depression, prevalence of neuropsychiatric and behavioural symptoms, level of daily functioning, PWDs' general health or comorbidities prevalent in addition to the dementia (only supported for proxy ratings), as well as caregivers' burden and level of distress.
- PWDs' QoL is probably not influenced by caregivers' level of depression.
- PWD's QoL may be predicted by caregivers' QoL, support caregivers receive from family and friends (only supported for QOL-ADproxy), caregivers' health and caregivers' perceived economic burden.

5.3.2.5 Quality of life: caregiver's perspective

Caregivers' proxy ratings decreased significantly with progressing dementia as can be seen from the data in **Table 26**.

Table 26: One-way ANOVA: differences between caregivers' mean proxy ratings of patients' QoL according to dementia severity at baseline

	Mean \pm SE [Range: minimum – maximum]				$F_{2,48}^*$	p
	Very mild $n = 19$	Mild $n = 25$	Moderate $n = 8$	Severe $n = 1$		
QOL-ADproxy	37.3 \pm 1.3 [25 – 47]	35.0 \pm 1.0 [22 – 42]	29.3 \pm 2.5 [17 – 42]	30.0 \pm - [-]	9.15	.001

Key. QoL, quality of life; QOL-ADproxy, Quality of Life-Alzheimer's Disease Scale proxy rating.

*The QoL ratings from the one person with severe dementia were excluded from this one-way ANOVA.

Patient ratings of their own QoL were on average higher (38.0 \pm 0.8) than caregivers' proxy ratings (34.8 \pm 0.8) as has been shown in Table 21 (p. 175). Caregivers also rated patients' QoL lower than patients themselves in every severity group (CDR of 0.5, 1 or 2) as **Figure 10** illustrates.

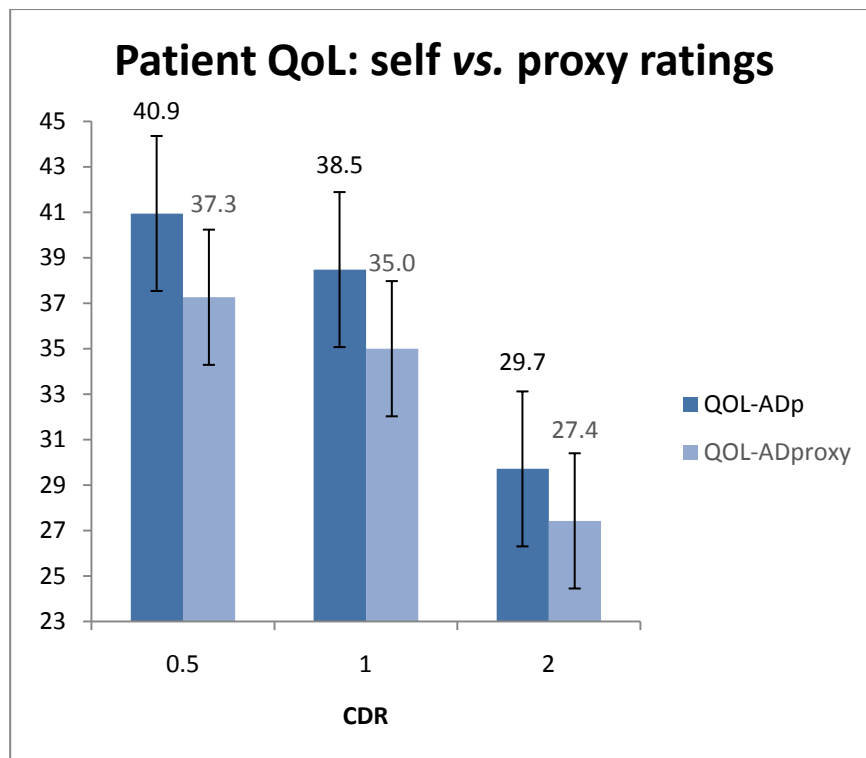


Figure 10: Patients vs. caregiver ratings (mean QOL-AD scores) of patients' QoL at baseline

Key. PWDs', persons' with dementia; QoL, quality of life; QOL-ADp, Quality of Life-Alzheimer Disease Scale patient rating; QOL-ADproxy, Quality of Life-Alzheimer Disease Scale proxy rating; CDR, Clinical Dementia Rating Scale.

Note. The difference between severity groups was statistically significant: QOL-ADp ($F_{2,48} = 16.16, p < .001$); QOL-ADproxy ($F_{2,48} = 9.15, p < .001$). The difference between patient and proxy ratings approached statistical significance for CDR: 1 ($F_{17,15} = 2.29, p = .057$).

Overall, caregivers agreed with patients with regards to factors predicting patients' QoL. However, some differences could be observed:

- caregivers' distress was a more significant predictor ($r = -.454, p = .001$) for carers' proxy ratings than for PWDs' self ratings ($r = -.334, p = .015$);
- the overall score of how supported caregivers felt (measured using the MSPSS) was significantly correlated with caregivers ratings of PWDs' QoL ($r = .354, p = .009$) but only approached statistical significance with PWDs' own ratings of their QoL ($r = .267, p = .053$).

Interestingly, the number of hours caregivers spent to assist PWDs had no significant impact on carers' proxy ratings. However, caregivers' proxy ratings of patients' own QoL were statistically significantly correlated with a number of outcomes:

- stage of illness ($r = -.437, p = .001$),
- PWDs' QoL: patient ratings ($r = .688, p < .001$),
- PWDs' depressive symptoms ($r = -.435, p = .001$),
- neuropsychiatric and behavioural symptoms ($r = -.511, p < .001$),
- level of daily functioning ($r = -.489, p < .001$),
- PWDs' health status: proxy ratings ($r = -.447, p < .001$),
- caregivers' QoL ($r = .665, p < .001$),
- caregivers' level of burden ($r = -.627, p < .001$),
- caregivers' level of distress ($r = -.454, p = .001$),
- perceived social support total score ($r = .354, p = .009$),
- caregivers' perceived economic burden ($r = -.450, p = .011$).

These correlations show that caregivers' proxy ratings were better if patients were at an earlier stage of illness; if patients' own QoL ratings were higher; if patients had fewer depressive and neuropsychiatric and behavioural symptoms; if patients were better functioning on a daily basis; and if patients had a better health status. Additionally, caregivers' ratings were higher if they felt less (financially) burdened and distressed and more supported by family and friends.

By including all clinical patient and caregiver outcomes in a stepwise linear regression analysis, the researcher was able to show that a caregiver's decision of how to rate patients' QoL (QOL-ADproxy) was best predicted by patients' (QOL-ADp) and caregivers' (QOL-ADc) own QoL ratings and carers' burden scores (BI) (see **Table 27**). These three variables together explained 65.8% of the variance of caregivers' total QOL-ADproxy scores (adjusted $R^2 = .66$), which indicates that the combination of all three factors was an important predictor for how caregivers rated patients' QoL. Ratings were better if patients' own ratings of their QoL were better; if caregivers' ratings of their own QoL were higher; and if caregivers felt less burdened.

Table 27: Summary of stepwise linear regression analysis for variables predicting caregiver ratings of PWDs' QoL (QOL-ADproxy)

	<i>B</i>	<i>SE B</i>
Step 1		
Constant	8.13	4.10
QOL-ADp	0.70	0.11***
Step 2		
Constant	-2.80	4.64
QOL-ADp	0.45	0.12***
QOL-ADc	0.51	0.13***
Step 3		
Constant	8.05	5.06
QOL-ADp	0.31	0.11**
QOL-ADc	0.46	0.12***
BI	-0.15	0.04**

Key. QOL-AD p, Quality of Life-Alzheimer's Disease Scale patient rating; QOL-AD c, Quality of Life-Alzheimer's Disease Scale caregiver rating; BI, Zarit Burden Interview; *B*, unstandardised regression coefficient; *SE B*, standard error of *B*. Note. Adj. $R^2 = .45$ for Step 1; adj. $R^2 = .57$ for Step 2; adj. $R^2 = .66$ for Step 3 ($ps < .010$).

*** $p < .001$; ** $p < .010$

In a different model, the researcher controlled for all caregiver outcomes and found that in addition to patients' QOL-AD ratings patients' neuropsychiatric and behavioural symptoms also strongly predicted how caregivers would evaluate PWDs' QoL. Both variables together explained 51.0% of the variance of QOL-AD proxy scores.

Based on the above results **the hypothesis that caregivers' proxy ratings of PWDs' QoL are predicted by caregivers' level of distress was supported.**

5.3.2.6 Depression

The following results relate to the hypothesis that PWDs' QoL is predicted by depression (as listed under point 1.a of chapter 3.3, p. 114).

The average CSDD score was 6.3 ± 0.6 ranging from 0 – 22 points at baseline indicating that some significant depressive symptoms might have been present in most PWDs. A detailed look into groups by cut-off scores revealed that four patients (7.6%) were affected by a probable or definite

major depression (see **Table 28**). Of those four patients, there were three (75.0%) who were on anti-depressive medication. At follow-up, 9.4% of PWDs ($n = 3$) scored 11 points or more on the CSDD indicating a probable or definite major depression. All these patients took anti-depressants at the time of the second interview.

Table 28: PWDs' depression levels at baseline

Degree of depression	CSDD score	<i>n</i>	%
Absence of significant depressive symptoms	0 – 5	25	47.2
	6 – 10	24	45.3
Probable major depression	11 – 18	2	3.8
Definite major depression	19 – 38	2	3.8

Key. PWDs', persons' with dementia; CSDD, Cornell Scale for Depression in Dementia.

Pearson's correlation showed that the following factors were associated most significantly with PWDs' prevalence of depressive symptoms:

- PWDs' QoL: patient ratings ($r = -.415, p = .002$),
- PWDs' QoL: proxy ratings ($r = -.435, p = .001$),
- neuropsychiatric and behavioural symptoms ($r = .679, p < .001$),
- caregivers' level of burden ($r = .706, p < .001$),
- caregivers' level of distress ($r = .595, p < .001$).

These correlations indicate that depressive symptoms in patients negatively impacted their own QoL and caregivers' subjective level of burden and distress. PWDs who exhibited neuropsychiatric and behavioural symptoms were more likely to be depressed as well. **The hypothesis that PWDs' QoL is predicted by depression was supported based on this data.**

5.3.2.7 Neuropsychiatric and behavioural symptoms

The results below relate to the following hypothesis: PWDs' QoL is predicted by neuropsychiatric and behavioural symptoms (as listed under point 1.a of chapter 3.3, p. 114).

At baseline, the mean total NPI score was highest for participants with mixed dementia (16.0 points out of 120), followed by participants with VD (12.9/120) and lowest for persons with AD (7.2/120) as shown in Table 21 (p. 175). The relatively low mean scores in each group are not unexpected, since the majority of patients were at an early stage of dementia at baseline but some neuropsychiatric and behavioural symptoms are more common at the more moderate or severe stages of dementia (Srikanth, Nagaraja, & Ratnavalli, 2005), even though different symptoms progress in different ways (Aalten, de Vugt, Jaspers, Jolles, & Verhey, 2005). Also, it is unlikely that a PWD will experience many of these symptoms at the same time. It is more likely that the majority of patients will experience some of these symptoms at some stage of their dementia. **Figure 11** demonstrates that apathy was the most prevalent neuropsychiatric symptom at baseline, observed in 52.8% of PWDs. Agitation/aggression, depression and anxiety were symptoms common in almost every second PWD.

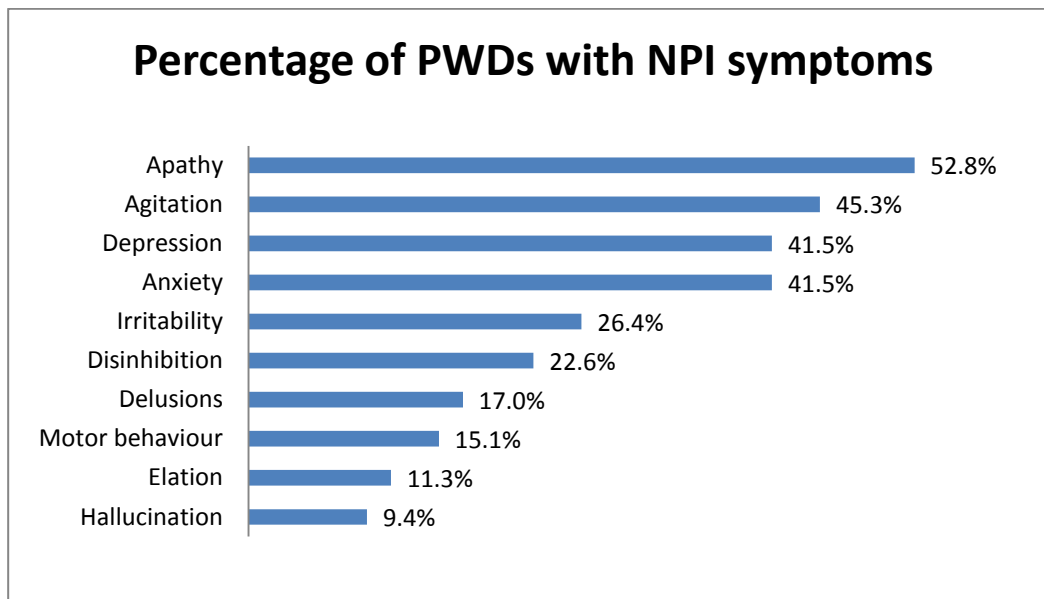


Figure 11: Percentage of PWDs exhibiting NPI symptoms at baseline
Key. PWDs, persons with dementia; NPI, Neuropsychiatric Inventory.

If PWDs exhibited aberrant motor behaviours and apathy, then these symptoms occurred on average more frequently (several times per week) than any other neuropsychiatric behaviour or symptoms, as **Figure 12** illustrates.

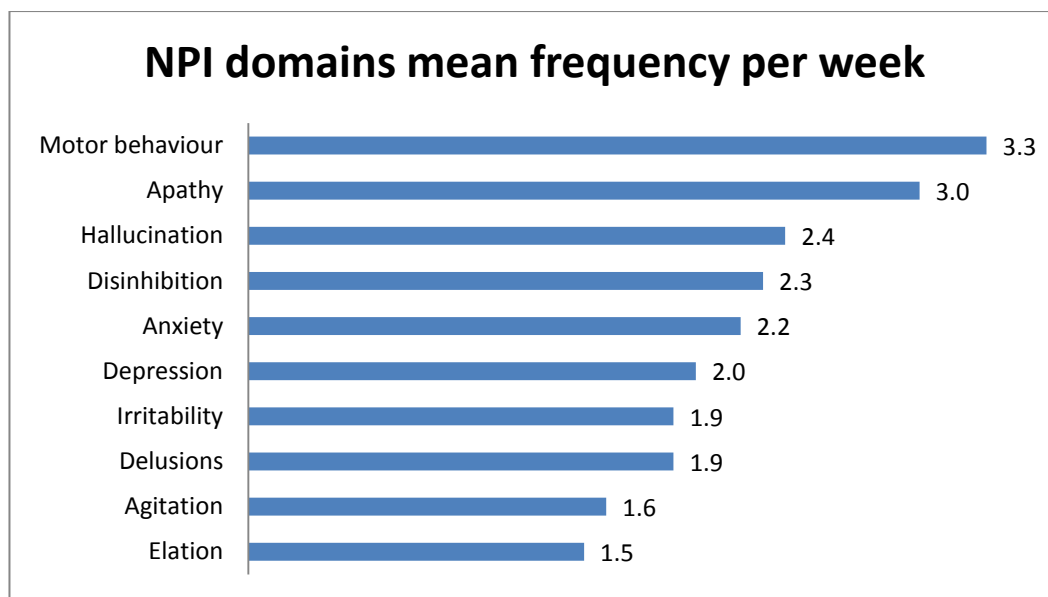


Figure 12: Mean frequency scores of NPI symptoms at baseline

Key. NPI; Neuropsychiatric Inventory. Frequency is rated as: 1 – Occasionally: less than once a week; 2 – Often: about once per week; 3 – Frequently: several times per week but less than every day; 4 – Very frequent: daily or essentially continuously present.

Depression and delusions were on average the most severe symptoms, as shown in **Figure 13**.

Interestingly, even though PWDs seemed only sad or depressed about once a week (less frequent than other symptoms) the depression was distressing and difficult to alleviate.

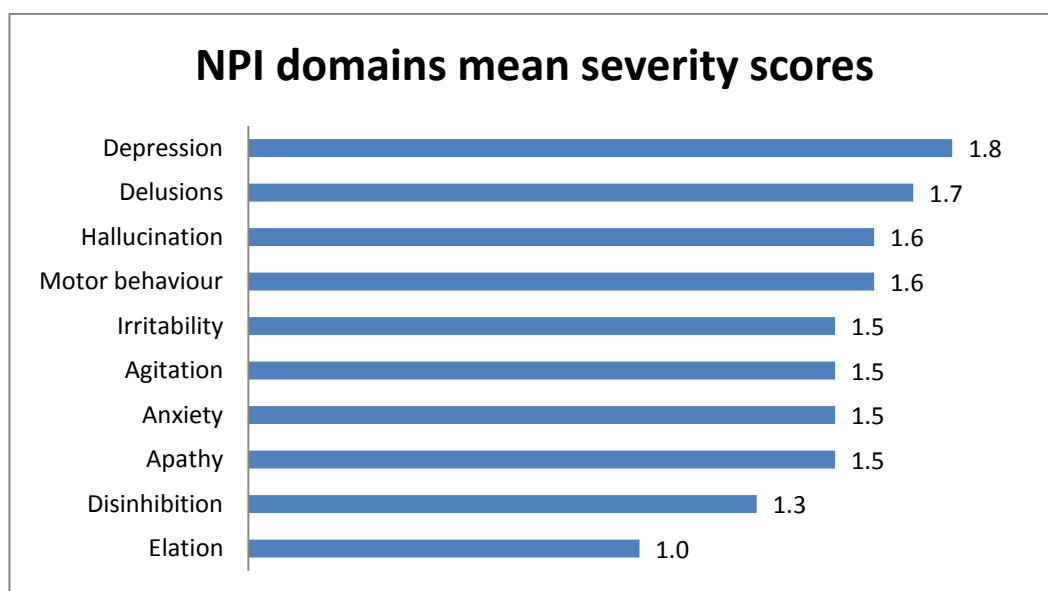


Figure 13: Mean severity scores of NPI symptoms at baseline

Key. NPI, Neuropsychiatric Inventory. Severity is rated as: 1 – Mild: produces little distress in the patient; 2 – Moderate: more disturbing to the patient but can be redirected by the caregiver; 3 – Severe: very disturbing to the patient and difficult to redirect.

Figure 14 illustrates that the average NPI domain scores (frequency multiplied by severity) were highest for aberrant motor behaviours, apathy, delusions and hallucinations.

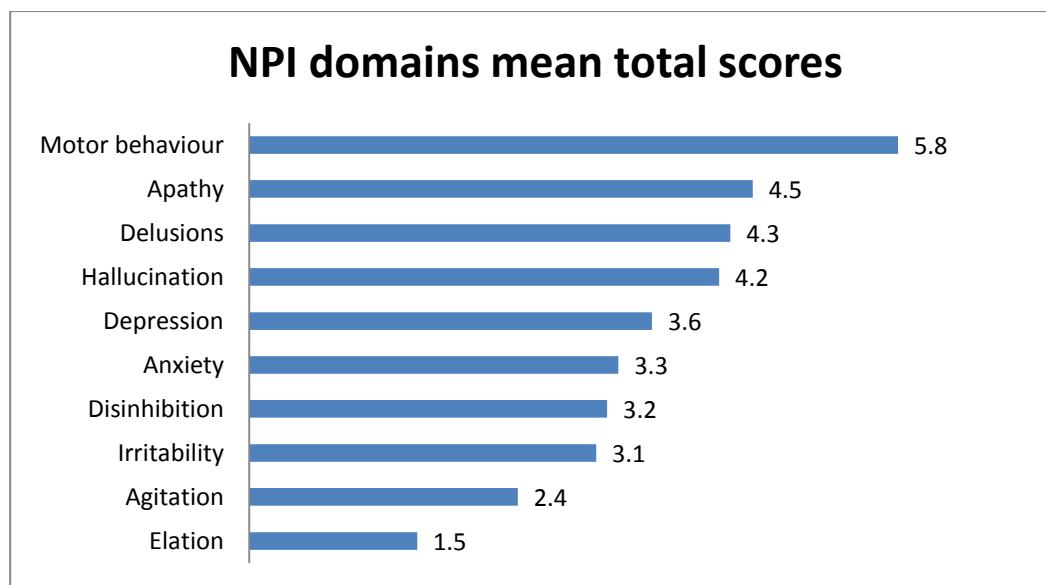


Figure 14: Mean NPI scores (frequency x severity) at baseline

Key. NPI; Neuropsychiatric Inventory.

Pearson's correlations were performed for the single NPI items and some of the clinical QoL outcomes. They showed that 'apathy' and 'disinhibition' were the items most often significantly correlated with outcomes such as caregiver distress (NPI-D: $r = .506, p < .001$, : $r = .615, p < .001$ respectively) and burden (BI: $r = .382, p = .005$, : $r = .404, p < .003$ respectively), caregiver QoL (QOL-ADc: $r = -.351, p = .01$, disinhibition) and PWDs' QoL (QOL-ADp: $r = -.356, p = .009$, : $r = -.431, p = .001$ respectively and QOL-ADproxy: $r = -.367, p = .007$, : $r = -.438, p = .001$ respectively).

These correlations show that PWDs who presented symptoms of apathy and/ or disinhibition had a significantly lower QoL (patient and caregiver perspective). Caregivers of those patients were more likely to be burdened, distressed and rate their own QoL lower. From the above findings it is possible to conclude that apathy was an important QoL predictor because it was the symptom prevalent in the highest percentage of participants (52.8%) and one of the most frequently occurring symptoms (several times per week but less than every day). Disinhibition, however, was not the most prevalent, frequent or severe symptom, which supports the conclusion that disinhibition is a symptom which does not occur in many patients or often at an early stage of dementia. But if a patient acts disinhibited, this behaviour causes a significant level of distress in caregivers and negatively impacts on patients' and caregivers' QoL.

The following is a list of Pearson's correlations linked most strongly with PWDs' neuropsychiatric and behavioural symptoms (NPI total score):

- PWDs' QoL: patient ratings ($r = -.403, p = .003$),
- PWDs' QoL: proxy ratings ($r = -.511, p < .001$),
- PWDs' depressive symptoms ($r = .679, p < .001$),
- caregivers' level of burden ($r = .527, p < .001$),
- caregivers' level of distress ($r = .838, p < .001$),
- perceived social support from significant other ($r = -.382, p = .005$).

These correlations indicate that even though the mean NPI scores in all pathological groups were relatively low, the presence of neuropsychiatric and behavioural symptoms still had a significant negative impact on patients' QoL from both the PWD's as well as the caregiver's perspective. PWDs with neuropsychiatric and behavioural symptoms were more likely to also show symptoms of depression. Further, these data illustrate that caregivers of these patients had higher levels of burden and distress and they felt less supported by family or friends. **The hypothesis that PWDs' QoL is predicted by neuropsychiatric and behavioural symptoms was therefore supported.**

5.3.2.8 Daily functioning

The results which follow relate to the hypothesis that PWDs' QoL is predicted by their daily functioning (as listed under point 1.a of chapter 3.3, p. 114). As outlined in Table 21 (p. 175), participants diagnosed with VD were on average more severely impaired in their functional abilities (12.8 out of 60 points with more points indicating a more severe level of impairment) than participants with mixed dementia (9.8/60) or AD (6.3/60). Across all three groups these results indicate a beginning or mild level of impairment. The results are presented according to the different domains of patients' functional competence:

ADLs: eating, drinking, dressing, hygiene, teeth, bath/shower, toilet/commode, transfer, mobility, orientation to time, orientation to place, communication;

IADLs: preparing food, preparing drink, telephone, housework/gardening, shopping, finances, games/hobbies, transport (driving).

On average, one fifth (20.3%) of PWDs were to some extent impaired in their basic activities of daily living. PWDs' orientation to time and space as well as their ability to communicate were the most severely impaired ADLs (see **Figure 15**). Participants' temporal orientation was limited in 3 out of 4 patients (73.6%). Because participants' temporal orientation was so significantly more impaired than other ADLs the researcher also calculated the median frequency of ADL impairments in addition to the mean which resulted in 17.9% of patients being to some degree impaired in their ability to perform tasks of daily living.

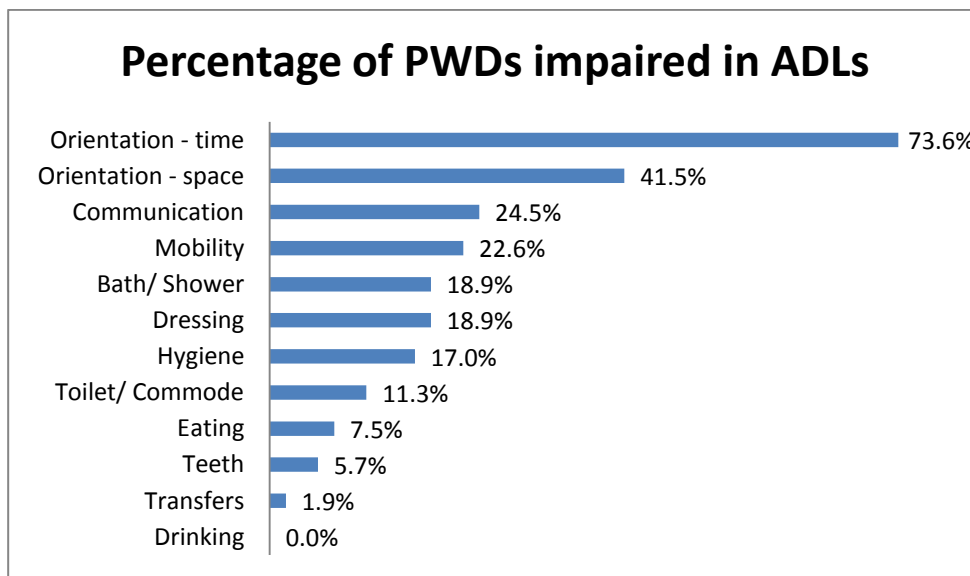


Figure 15: Percentage of PWDs with ADL impairments at baseline

Key. PWDs, persons with dementia; ADLs, activities of daily living.

Figure 16 shows that patients' temporal orientation was on average most severely impaired by far, with an average of 1.2 points. This indicates that most patients were unaware of time or day or date but seemed unconcerned. Patients' geographical orientation and their ability to communicate and walk were also significantly limited.

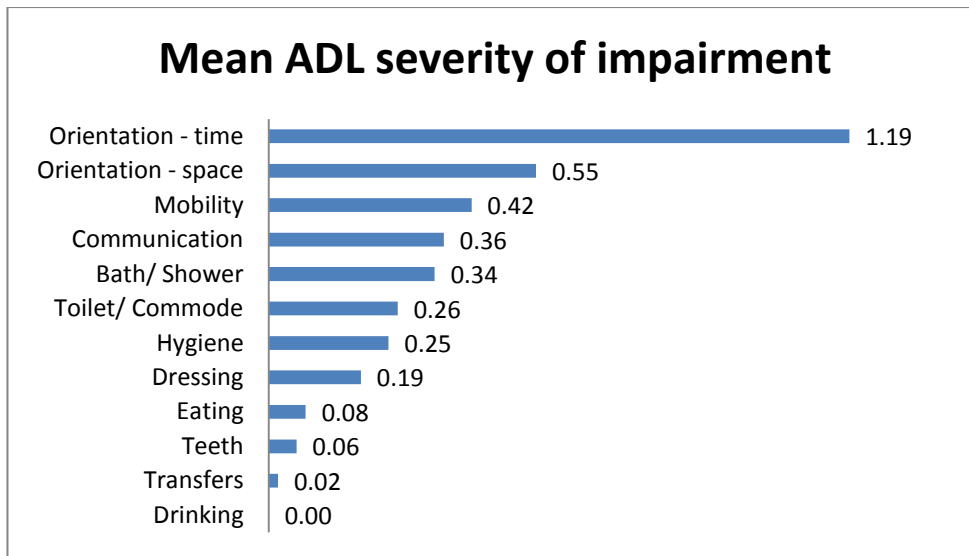


Figure 16: Mean severity scores of ADL impairments at baseline

Key. ADL, activity of daily living.

Figure 17 shows that on average more than one-third of PWDs (38.4%) were to some extent impaired in their ability to perform IADLs at baseline. The median IADL impairment of 41.5 % was considerably higher than the median ADL impairment of 17.9%. This indicates that more than twice as many patients were limited in the more complex activities of daily living as compared to the basic ones at baseline.

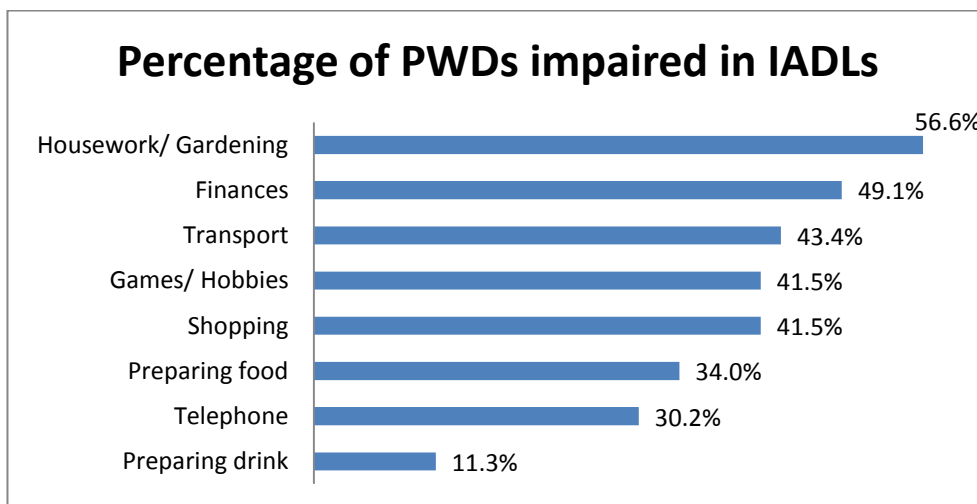


Figure 17: Percentage of PWDs with IADL impairments at baseline

Key. PWDs, persons with dementia; IADLs, instrumental activities of daily living.

Figure 18 demonstrates that most IADLs, except for being able to prepare a cup of tea or coffee, were more equally impaired than the ADLs. Most IADLs were also more severely impaired (average 0.6 points) than the ADLs (average 0.3 points). PWDs' ability to help with housework and gardening was most impaired.

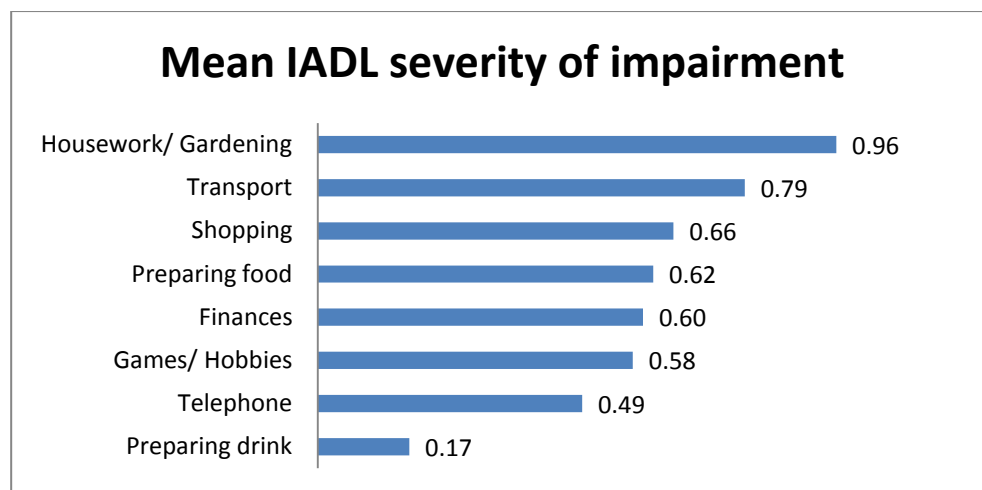


Figure 18: Mean severity scores of IADL impairments at baseline

Key. IADL, Instrumental activity of daily living.

PWDs' ability to perform ADLs and IADLS was one of the most prominent factors predicting QoL.

The level of daily functioning (BADLS) was linked to the majority of outcome measures of which the most significant ones are listed here:

- stage of illness ($r = .614, p < .001$),
- PWDs' QoL: patient ratings ($r = -.546, p < .001$),
- PWDs' QoL: proxy ratings ($r = -.489, p < .001$),
- caregivers' level of burden ($r = .387, p = .004$),
- caregivers' level of distress ($r = .384, p = .005$),
- number of formal care contacts ($r = .391, p = .004$),
- length of formal care contacts ($r = .660, p < .001$),
- time spent on informal care ($r = .561, p < .001$).

These correlations show that PWDs were more functionally impaired if they were more progressed in their illness. These data show further that PWDs who were more impaired in their ADLs and IADLs had a lower QoL (patient and caregiver perspective); their caregivers felt more burdened and distressed and they received more and longer formal care contacts than patients who were able to function on a higher level. More functionally impaired PWDs also required more care time provided by their family-caregivers. After splitting the overall BADLS score into ADL and IADL, the researcher found that the more complex activities of daily living were more strongly

correlated with most of the QoL outcomes listed in **Table 29** than the basic activities (except for BI and NPI-D):

Table 29: Comparison between ADL and IADL Pearson's correlations

	ADL	IADL
QOL-ADp	-.490 ^{**}	-.509 ^{**}
QOL-ADproxy	-.400 ^{**}	-.490 ^{**}
CSDD	.206	.294 ^{***}
NPI	.238	.376 ^{**}
QOL-ADc	-.227	-.292 ^{***}
BI	.298 ^{***}	.406 ^{**}
NPI-D	.305 ^{***}	.385 ^{**}

Key. QOL-ADp, Quality of Life-Alzheimer's Disease Scale patient rating; QOL-ADproxy, Quality of Life-Alzheimer's Disease Scale proxy rating; CSDD, Cornell Scale for Depression in Dementia; NPI, Neuropsychiatric Inventory; QOL-ADc, Quality of Life-Alzheimer's Disease Scale caregiver rating; BI, Zarit Burden Interview; NPI-D, Neuropsychiatric Inventory-Distress scale.

*** $p < .001$; ** $p < .010$

It seems that the level of IADL impairment is a better predictor of PWDs' and caregivers' QoL than the level of ADL limitation, at least at an earlier stage of dementia. **The hypothesis that PWDs' QoL is predicted by their level of daily functioning was supported.**

5.3.2.9 Health

The health results relate to the hypothesis that PWDs' QoL is predicted by their general health or comorbidities prevalent in addition to the dementia (as listed under point 1.a of chapter 3.3, p. 114). Overall the number of possible health problems, other than the dementia, was relatively low and not very severe. Similar to ratings of patients' QoL, considering the total sample caregivers' average proxy ratings (Comorbidities proxy) were higher (13.5 ± 1.2) than patients' average self ratings (Comorbidities p: 9.8 ± 0.9). As can be seen from the data in Table 21 (p. 175) amongst the different pathological groups, patients with VD had the most or most severe health problems from their caregivers' point of view. From the patients' perspective those with mixed dementia were most affected by their health.

Caregiver's QoL (QOL-ADc) was the only clinical outcome which significantly correlated with patients' self rated health status ($r = -.315$, $p = .021$). This indicates that caregivers had a better

QoL if they looked after a PWD who had fewer or less severe health problems in addition to the dementia (patient perspective).

Caregivers' proxy-ratings of patients' health resulted in far more correlations which are listed here:

- stage of illness ($r = .420, p = .003$),
- PWDs' QoL: patient ratings ($r = -.471, p < .001$),
- PWDs' QoL: proxy ratings ($r = -.447, p = .001$),
- level of daily functioning ($r = .502, p < .001$),
- caregivers' level of burden ($r = .324, p = .018$).

These findings allow the following conclusions: caregivers rated the health status of the PWD as being better if patients were at an earlier stage of dementia and less functionally impaired. Also, caregivers felt less burdened if they looked after a person with fewer or less severe comorbidities. In this case caregivers and PWDs also rated the PWD' QoL higher. Based on these findings, **the hypothesis that PWDs' QoL is predicted by their general health or comorbidities prevalent in addition to the dementia was supported regarding the caregiver perspective (proxy ratings of patients' health status) but was not supported for the patient perspective (self rated health status).**

5.3.3 Clinical measures of caregiver quality of life

The measures were first analysed in a descriptive way, using the baseline data, followed by an evaluation of their quality as predictors of caregivers' QoL. **Table 30** represents caregivers' clinical characteristics.

Table 30: Caregivers' mean clinical scores at baseline for total sample and according to PWDs' pathology

	Mean \pm SE [Range: minimum – maximum]				$F_{2,50}$	p
	Total sample $n = 53$	Alzheimer's dementia $n = 31$	Vascular dementia $n = 14$	Mixed dementia $n = 8$		
QOL-ADc	40.5 \pm 0.7 [26 – 52]	41.7 \pm 0.9 [29 – 52]	38.5 \pm 1.3 [26 – 47]	39.3 \pm 1.7 [33 – 47]	2.40	.101
BI	22.9 \pm 1.9 [3 – 64]	21.0 \pm 2.1 [3 – 62]	28.1 \pm 4.6 [8 – 64]	21.3 \pm 5.3 [7 – 52]	1.39	.260
NPI-D	5.7 \pm 0.9 [0 – 34]	4.6 \pm 0.9 [0 – 15]	7.4 \pm 1.5 [0 – 17]	7.1 \pm 3.9 [0 – 34]	1.10	.341
GDS	11.5 \pm 0.3 [7 – 18]	12.0 \pm 0.4 [9 – 18]	11.2 \pm 0.7 [8 – 16]	10.3 \pm 0.8 [7 – 13]	2.07	.137
MSPSS	69.1 \pm 1.3 [26 – 84]	69.4 \pm 2.0 [26 – 84]	70.9 \pm 1.8 [60 – 80]	64.6 \pm 2.7 [55 – 74]	1.11	.336
Comorbidities c	10.0 \pm 1.1 [0 – 30]	9.5 \pm 1.5 [0 – 30]	12.8 \pm 2.1 [2 – 25]	6.9 \pm 2.3 [1 – 20]	1.52	.228

Key. PWDs', persons' with dementia; QOL-ADc, Quality of Life-Alzheimer's Disease Scale caregiver rating; BI, Zarit Burden Interview; NPI-D, Neuropsychiatric Inventory-Distress Scale; GDS, Geriatric Depression Scale; MSPSS, Multidimensional Scale of Perceived Social Support; Comorbidities c, caregivers' self rated health status.

Interestingly, unlike to the patient QoL outcomes, no statistically significant differences between pathological groups were observed for any of these caregiver measures (one-way ANOVA). In other words, outcomes such as the level of burden and distress or QoL *per se* are experienced in a similar way by caregivers of people with dementia, regardless if they look after somebody with AD or VD. Possible explanations will be discussed in the next chapter.

5.3.3.1 *Quality of life*

These QoL results relate to the following hypotheses as listed under point 1.b of chapter 3.3 (p. 114):

- Caregivers' QoL might be predicted by the type and severity of dementia, PWDs' QoL, cognition, neuropsychiatric and behavioural symptoms, and health.
- Additionally, caregivers' QoL is possibly influenced by their own burden, level of distress as a reaction to PWDs' neuropsychiatric and behavioural symptoms, depression, support from family and friends, health, economic burden and gender (being female).
- Caregivers' QoL is probably not impacted on by PWDs' level of depression and functional impairment.

The average QOL-AD rating was 40.5 (± 0.7) out of a possible 52 points, which is higher than any of the patient QOL-AD ratings. Caregivers of patients with AD rated their QoL on average highest, followed by caregivers of persons with mixed dementia. Participants who cared for persons with VD had the lowest average QOL-AD scores, as can be seen from the table above (Table 30, p. 199).

Strongest correlations were found between caregivers' QoL and:

- PWDs' QoL: patient ratings ($r = .564, p < .001$),
- PWDs' QoL: proxy ratings ($r = .665, p < .001$),
- perceived social support total score ($r = .496, p < .001$),
- perceived social support from friends ($r = .367, p = .007$),
- perceived social support from significant other ($r = .551, p < .001$),
- caregivers' health status ($r = -.486, p < .001$),
- joint income/pension ($r = .384, p = .005$).

Some weaker but statistically significant relationships were observed between caregivers' QoL ratings and:

- the stage of dementia ($r = -.279, p = .043$),
- level of daily functioning ($r = -.284, p = .039$),
- caregivers' level of burden ($r = -.331, p = .015$),
- PWDs' health status: self ratings ($r = -.351, p = .021$).

These correlations showed that caregivers perceived their QoL as being better if patients' QoL ratings were higher (patient and caregiver perspective); if they had more support from friends and a significant other (which could be a family member or spouse); if caregivers had a better health status; and/or if they had a higher joint annual income/pension together with the PWD. There was also some evidence for a better caregiver QoL if patients were at an earlier stage of dementia, less functionally impaired and had a better health status; and if caregivers felt less burdened. One-way ANOVA showed that the mean caregiver ratings of their QoL were significantly lower ($F_{2,48} = 3.32, p = .044$) for those who looked after a person with moderate dementia (CDR score of 2) as compared to mild dementia.

Interestingly, caregivers' QoL was neither linked to their level of depression nor to the type of dementia or patients' level of cognitive impairment. Furthermore, carer QoL was also not predicted by their gender, distress, or by patients' neuropsychiatric and behavioural symptoms, except for 'disinhibition'. The latter was significantly negatively linked to the total QOL-ADc score ($r = -.351, p = .001$). Additionally, there was no correlation with the time professional or family-caregivers spent assisting PWDs or with the number of formal care contacts.

Stepwise linear regression analysis showed that caregivers' QoL was best predicted by their QOL-AD proxy ratings, their health status and by the level of support caregivers received from family and friends (**Table 31**). These three variables together explained 70% of the variance of caregivers' total QOL-ADc scores. In a different model, the researcher controlled for all patient outcomes

(except pathology) and found that the carers' health status and social support still explained 48.1% of the variance.

Table 31: Summary of stepwise linear regression analysis for variables predicting caregivers' QoL (QOL-ADc)

	<i>B</i>	<i>SE B</i>
Step 1		
Constant	20.69	3.08
QOL-ADproxy	0.57	0.87***
Step 2		
Constant	24.83	2.79
QOL-ADproxy	0.52	0.75***
Comorbidities caregiver	-0.25	0.06***
Step 3		
Constant	16.63	3.17
QOL-ADproxy	0.42	0.07***
Comorbidities caregiver	-0.27	0.05***
MSPSS	0.17	0.04***

Key. QOL-AD proxy, Quality of Life-Alzheimer's Disease Scale proxy rating; CDR, Clinical Dementia Rating Scale; Comorbidities caregiver, caregivers' self rated health status; *B*, unstandardised regression coefficient; *SE B*, standard error of *B*.

Note. Adj. R^2 = 0.45 for Step 1; adj. R^2 = 0.60 for Step 2; adj. R^2 = 0.70 for Step 3 (***) $p < .001$.

*** $p < .001$

Based on these findings the following hypotheses were supported:

- Caregivers' QoL might be predicted by the severity of dementia, PWDs' QoL and health (patient perspective).
- Additionally, caregivers' QoL is possibly influenced by their own burden, support from family and friends, health and economic burden (income).
- Caregivers' QoL is probably not impacted on by PWDs' level of depression.

The following hypotheses were not supported:

- Caregivers' QoL might be predicted by the type of dementia, PWDs' cognition, depression, neuropsychiatric and behavioural symptoms, and health (caregiver perspective).
- Caregivers' QoL is possibly influenced by their level of distress as a reaction to PWDs' neuropsychiatric and behavioural symptoms, depression and gender (being female).
- Caregivers' QoL is probably not impacted on by PWDs' functional impairment.

5.3.3.2 Subjective burden

The following results relate to the hypothesis that caregivers' QoL is possibly influenced by their burden (as listed under point 1.b of chapter 3.3, p. 114).

The average burden score was 22.9 (± 1.9) whereby caregivers of persons with VD had the highest average burden score (Table 30, p. 199). It can be seen from the data in **Table 32** that more than half of those surveyed felt no or little burden (52.8%) and the other half felt mainly mild to moderate burden. A small but significant number of caregivers ($n = 5$), however, reported a moderate severe or even severe level of burden at baseline.

Table 32: Severity of caregiver burden at baseline

Severity of burden	BI score	<i>n</i>	%
No – little	0 – 20	28	52.8
Mild – moderate	21 – 40	20	37.7
Moderate – severe	41 – 60	3	5.7
Severe	61 – 88	2	3.8

Key. BI, Zarit Burden Interview.

Surprisingly, the total BI scores and the total QOL-ADc ratings were only moderately correlated ($r = -.331$ $p = .015$). Nevertheless, strong evidence of carers' burden being a QoL predictor was

found considering the significant correlations between the total BI score and the following outcomes:

- PWDs' QoL: patient ratings ($r = -.480, p < .001$),
- PWDs' QoL: proxy ratings ($r = -.627, p < .001$),
- PWDs' depressive symptoms ($r = .706, p < .001$),
- neuropsychiatric and behavioural symptoms ($r = .527, p < .001$),
- level of daily functioning ($r = .387, p = .004$),
- caregivers' level of distress ($r = .520, p < .001$),
- perceived social support total score ($r = -.370, p = .006$),
- time spent on informal care ($r = .369, p = .007$).

These correlations indicate that caregivers felt less burdened if they had a better QoL; if the PWD had a better QoL (patient and caregiver perspective); if the PWD was less depressed, had fewer NPI symptoms and was less functionally impaired. Further, it can be concluded that caregivers felt more burdened if they were more distressed, less supported by family and friends and spent more time looking after the PWD. **The hypothesis that caregivers' QoL is possibly influenced by their own burden was supported based on these findings.**

5.3.3.3 Distress

The following results for distress relate to the hypothesis that caregivers' QoL is possibly influenced by their level of distress as a reaction to PWDs' neuropsychiatric and behavioural symptoms (as listed under point 1.b of chapter 3.3, p. 114).

Overall carers' distress was relatively low with an average of 5.7 (± 0.9) of a possible 50 points. The highest levels of distress were caused by participants with VD 7.4 (± 1.5) and the lowest distress ratings were taken from caregivers of persons with AD 4.6 (± 0.9), as can be seen from the data in **Table 30** (p. 199). The widest array of reactions, however, was observed for carers of persons with mixed dementia with scores ranging from 0 – 34 points. The following behaviours or symptoms

showed the strongest correlations with carer distress at the $p < .001$ level: aberrant motor behaviours, disinhibition, irritability and apathy. Aberrant motor behaviours and apathy scored highest on the average domain sum (frequency x severity). Interestingly, disinhibition and irritability were amongst the lowest average domain scores. However, both symptoms were amongst the ones caregivers reacted most strongly to. Irritability was the only symptom which caused some distress for every caregiver (of a PWD who was abnormally irritable) resulting in the highest mean NPI-D score of 2.9 points. Disinhibition, anxiety and depression caused on average a mild to moderate level of distress (**Figure 19**).

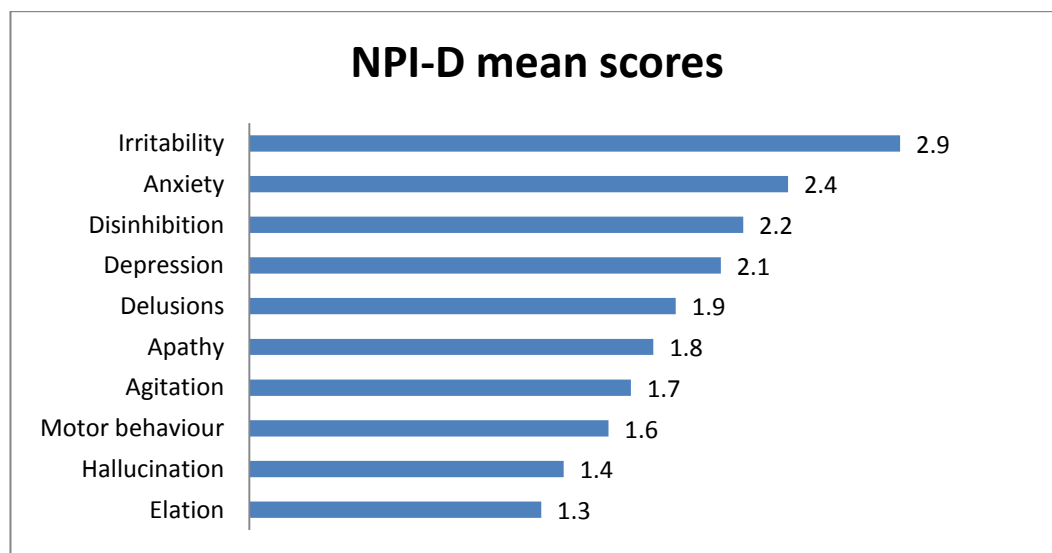


Figure 19: Carers' mean level of distress as reaction to NPI symptoms at baseline

Key. NPI-Distress; Neuropsychiatric Inventory-Distress scale. Level of distress is rated as: 1 – Minimal; 2 – Mild; 3 – Moderate; 4 – Severe; 5 – Extreme.

Caregivers' level of distress as a reaction to patients' neuropsychiatric and behavioural symptoms was a strong predictor of patients' QoL, as shown by the following highly significant correlations:

- PWDs' QoL: proxy ratings ($r = -.454, p = .001$),
- PWDs' depressive symptoms ($r = .595, p < .001$),
- neuropsychiatric and behavioural symptoms ($r = .838, p < .001$),
- level of daily functioning ($r = .384, p = .005$),
- caregivers' level of burden ($r = .520, p < .001$).

Some weaker relations were observed between caregivers' distress ratings and:

- PWDs' QoL: patient ratings ($r = -.334, p = .015$),
- time spent on informal care ($r = .334, p = .015$).

These correlations show that caregivers with an increased distress level rated patients' QoL lower and looked after patients with more depressive and neuropsychiatric and behavioural symptoms and who were more functionally impaired. The data also strongly suggest that caregivers who felt more distressed were more burdened. There was some indication that more distressed caregivers looked after PWDs with a lower QoL who required more informal caregiving time. Surprisingly, no significant correlation was found between caregivers' distress and QoL ratings (QOL-ADc). However, the correlation approached significance at a $p = .078$ level at baseline and at a $p = .089$ level at follow-up. **The hypothesis that caregivers' QoL is possibly influenced by their level of distress as a reaction to PWDs' neuropsychiatric and behavioural symptoms was supported but based on data which did not reach statistical significance.** However, distress was strongly predicted by caregiver burden. Overall, caregiver distress might be less a predictor of caregiver QoL than an indicator for patient outcomes.

5.3.3.4 Depression

The following results relate to the hypothesis that caregivers' QoL is possibly influenced by their levels of depression (as listed under point 1.b of chapter 3.3, p. 114).

Even though the majority of caregivers reported feeling no or little burden (52.8%), almost two thirds of caregivers were depressed or had symptoms of depression (60.4%) as can be seen from the data in **Table 33**. However, only 15.1% were prescribed mental health medication.

Table 33: Caregivers' depression levels at baseline

Interpretation GDS	GDS score	<i>n</i>	%
Normal range	0 – 10	21	39.6
May indicate depression	11 – 30	32	60.4

Note. GDS, Geriatric Depression Scale.

Correlations were found only between caregivers' depression scores and caregivers' level of burden (BI: $r = .307$ $p = .025$) as well as participants' joint income/pension ($r = -.359$, $p = .008$). Additionally, less impaired cognition in PWDs was related moderately to higher caregiver depression (3MS: $r = .289$, $p = .037$). A one-way ANOVA confirmed the first correlation by showing significant differences for caregivers' mean depression scores between income groups ($F_{2,50} = 3.71$, $p = .032$) which is a finding discussed in more detail in section 5.8.5 (p. 304) on economic burden. Stepwise linear regression analysis further confirmed these findings with a model where joint income, caregiver burden (BI), patient cognition (3MS) and type of dementia predicted 30% of GDS variance (adjusted $R^2 = .297$).

These findings suggest that caregivers were more likely to be depressed if they felt more burdened, were living on a lower joint income/pension with the PWD and if they looked after a less cognitively impaired person who had AD rather than VD or mixed dementia.

Interestingly, significant correlations were also observed between GDS scores and patients' age ($r = -.301$, $p = .030$) as well as caregivers' status as a Community Services Card holders ($r = -.283$, $p = .042$). This means caregivers were more likely to be depressed if they looked after younger PWDs and held a Community Services Card. After splitting the data into those who had a GDS score of ≥ 11 (being possibly depressed) and those who had a GDS score of < 11 (being not depressed) it was found that caregivers who were depressed were less likely to have been hospitalised within the 3 months prior to baseline assessment ($r = -.311$, $p = .025$) and more likely to have utilised meals-on-wheels for the PWD ($r = .324$, $p = .020$).

Surprisingly, no significant correlation was found between caregivers' depression levels and caregivers' QoL ratings (QOL-ADc). **The hypothesis that caregivers' QoL is possibly influenced by their level of depression was not supported.**

5.3.3.5 Health

The following results relate to the hypothesis that caregivers' QoL is possibly influenced by their health (as listed under point 1.b of chapter 3.3, p. 114).

The number of possible health problems and their severity is comparable to the patient ratings of their health, except for mixed dementia. The total sample of caregivers scored an average of 10.0 points (± 1.1). Similar to caregivers' proxy ratings of patients' health, the average health score was highest for caregivers' of patients with VD (12.8 ± 2.1), as can be seen from the data in Table 30 (p. 199). Caregivers' health ratings were correlated with the following outcomes:

- caregivers' age ($r = .480, p < .000$),
- joint income/pension ($r = -.299, p = .030$),
- caregivers' QoL ($r = -.486, p < .000$).

These findings show that caregivers who had more severe health problems were more likely to be older have a lower joint income/pension with the PWD and a worse QoL. **The hypothesis that caregivers' QoL is possibly influenced by their health was therefore supported.**

5.3.3.6 Informal social support

The following results relate to the hypothesis that caregivers' QoL is possibly influenced by support from family and friends (as listed under point 1.b of chapter 3.3, p. 114).

Caregivers' perception of the level of support received from family members, from friends, and from significant others was a significant predictor of QoL. The average MSPSS rating was relatively high with 69.1 of a possible 84 points indicating a sufficient level of carer satisfaction with their informal support network. Interestingly, caregivers of patients with VD felt on average most supported and those of patients with mixed dementia felt least supported, as can be seen from

the data in Table 30 (p. 199). What is most striking about this observation is that the same VD caregiver group had on average also the lowest QoL ratings and the highest burden and distress scores. It has to be noted though that these differences were not statistically significant at baseline.

The total score of perceived social support was highly correlated with caregivers' QoL ($r = .496, p < .001$) and burden ($r = -.370, p = .006$). How supported caregivers felt seemed to impact on how they rated patients' QoL ($r = .354, p = .009$). There was also a relationship between social support and PWDs' neuropsychiatric and behavioural symptoms ($r = -.315, p = .022$). These findings indicate that caregivers who felt more supported by family and friends perceived their QoL as being better, they felt less burdened and they rated the PWD's QoL higher. These caregivers were also more likely to look after a patient with fewer NPI symptoms. **The hypothesis that caregivers' QoL is possibly influenced by support from family and friends was therefore supported.**

5.4 Prospective cohort study: follow-up

The following results relate to the hypothesis that similar QoL predictors can be observed over time (12 months) but their clinical values might deteriorate (as listed under point 1.c of chapter 3.3, p. 114). A one-way ANOVA analysis revealed that only some QoL outcomes changed significantly between baseline and follow-up assessment, indicating that similar predictors of QoL in dementia could be observed over 12 months. However, only PWDs' outcomes changed significantly. Caregiver outcomes remained stable over time.

5.4.1 Clinical measures of patient quality of life

A one-way ANOVA analysis based on matched pairs (i.e., the data collected from the remaining 33 follow-up participants were matched with the data collected from these 33 participants at baseline) showed that the following PWDs' outcomes changed significantly from baseline to follow-up assessment:

- stage of illness decreased; PWDs progressed to more severe stage ($F_{1,64} = 5.61, p = .021$);
- cognition decreased ($F_{1,63} = 7.88, p = .007$);
- neuropsychiatric and behavioural symptoms increased ($F_{1,64} = 5.62, p = .021$);
- level of daily functioning decreased ($F_{1,64} = 7.31, p = .009$);
- caregivers' level of distress ($F_{1,64} = 3.62, p = .062$) and length of formal care visits ($F_{1,62} = 3.84, p = .055$) increased almost significantly.

Table 34 gives an overview of those clinical patient QoL outcomes that had changed significantly between baseline and follow-up. Mean values are presented for the entire sample as well as split by pathological groups. A statistically significant difference was only observed for patients' level of functioning which was more impaired in participants with VD and mixed dementia as compared to AD ($F_{2,29} = 4.85, p = .015$).

Table 34: One-way ANOVA: differences between PWDs' mean clinical scores at follow-up according to pathology

	Mean \pm SE [Range: minimum – maximum]				$F_{2,29}$	p
	Total sample of patients $n = 33$	Alzheimer's dementia $n = 19$	Vascular dementia $n = 11$	Mixed dementia $n = 3$		
CDR	1.2 \pm 0.1 [0.5 – 3]	1.0 \pm 0.1 [0.5 – 2]	1.6 \pm 0.3 [0.5 – 3]	1.3 \pm 0.3 [1 – 2]	2.71	.083
3MS	63.9 \pm 2.3 [28 – 82]	65.5 \pm 2.8 [32 – 82]	60.6 \pm 4.8 [28 – 77]	66.3 \pm 7.5 [56 – 81]	0.44	.651
NPI	16.2 \pm 2.2 [0 – 54]	12.9 \pm 2.1 [4 – 35]	21.2 \pm 5.2 [0 – 54]	18.3 \pm 7.8 [4 – 31]	2.40	.109
BADLS	12.2 \pm 1.5 [0 – 41]	8.6 \pm 1.2 [0 – 19]	18.5 \pm 3.4 [4 – 41]	11.3 \pm 1.2 [9 – 13]	4.85	.015

Key. PWDs', persons' with dementia; CDR, Clinical Dementia Rating Scale; 3MS, Modified Mini-Mental State Examination; NPI, Neuropsychiatric Inventory; BADLS, Bristol Activities of Daily Living Scale.

5.4.1.1 Stage of illness

Table 35 illustrates that three quarters of patients were still in the early stages of dementia at baseline. However, 1 in 4 patients (24.3%) had advanced to a moderate or severe stage, which is a considerably higher number than at baseline. The deterioration of dementia was significant as a matched pair one-way ANOVA showed ($F_{1,64} = 5.61, p = .021$).

Table 35: Severity of dementia at baseline and follow-up

Baseline (<i>n</i> = 53)			Follow-up (<i>n</i> = 33)	
CDR score	<i>n</i>	%	<i>n</i>	%
0.5	19	35.8	5	15.2
1	25	47.2	20	60.6
2	8	15.1	6	18.2
3	1	1.9	2	6.1

Key. CDR, Clinical Dementia Rating Scale.

On average, persons with VD were at a moderate stage of illness (1.6 out of 3 points on the CDR) and persons with AD and mixed dementia at an earlier stage (1.0/1.3 points) as can be seen from the data in Table 34 (p. 210). At baseline, persons with mixed dementia, not VD, were on average most advanced in their illness. Persons with VD also advanced the most; on average 0.4 points on the CDR as **Figure 20** shows. Considering the entire baseline sample (*n* = 53), participants with mixed dementia actually improved on average in terms of the illness progression by -0.3 points. Since such an improvement is very unlikely it can be concluded that a higher percentage of participants from this group was lost to follow-up as compared to the other pathological groups. This was confirmed with a matched pair analysis which showed that there was no change in terms of illness progression for participants with mixed dementia (**Figure 20**). Also, the participants with mixed dementia who discontinued were the ones with mixed dementia at a more severe stage (average CDR score of 1.8) compared to those who continued (average CDR score of 1.3).

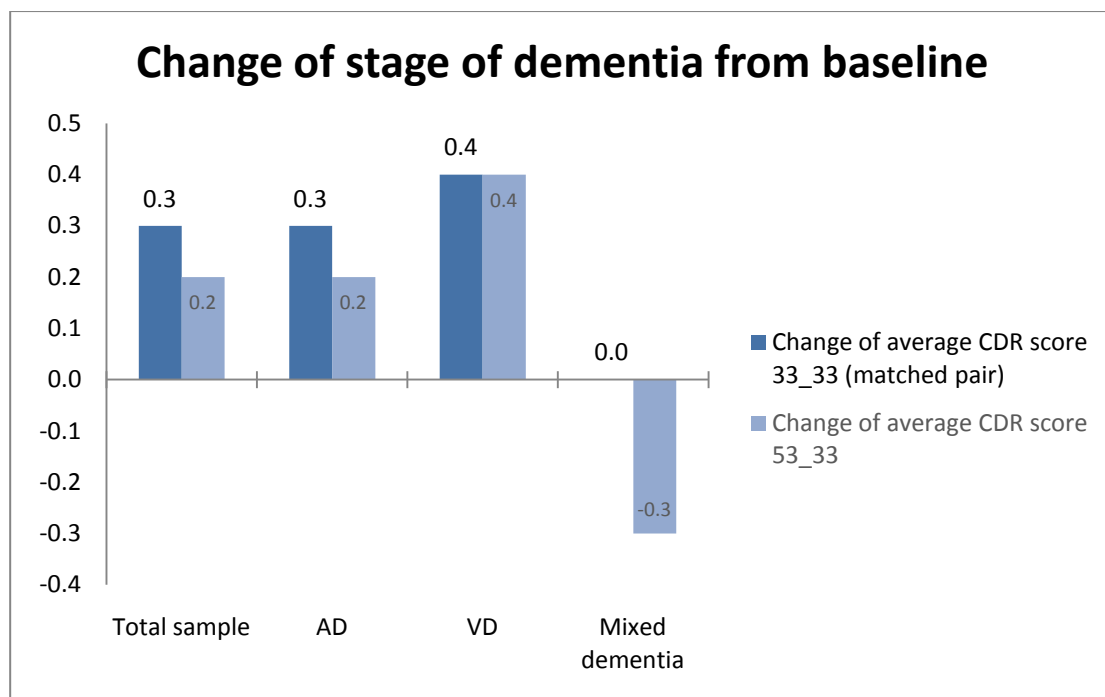


Figure 20: Change of stage of dementia from baseline (mean CDR scores)

Key. CDR, Clinical dementia Rating Scale; Modified Mini-Mental State Examination; AD, Alzheimer's dementia; VD, vascular dementia.

Note. Dark blue bars represent the change between baseline and follow-up based on a matched pair analysis where the data collected from the remaining 33 follow-up participants were matched with the data collected from these 33 participants at baseline ($n = 33$ at t_1 and $n = 33$ at t_2). Light blue bars represent the change between baseline and follow-up based on a non-matched pair analysis ($n = 53$ at t_1 and $n = 33$ at t_2).

In addition to the correlations observed at baseline, there was also a link between PWDs' stage of illness and their neuropsychiatric and behavioural symptoms at follow-up ($r = .394$, $p = .023$). This indicates that a later stage of dementia probably increases the likelihood for patients to develop such symptoms.

5.4.1.2 Cognition

At follow-up, persons with mixed dementia were on average the least cognitively impaired (66.3 points out of 100), closely followed by persons with AD (65.5 points). Participants with VD were on average most impaired in their cognition (60.6 points) as can be seen in Table 34 (p. 210). **Table 36** shows that only 15.2% still scored more than 78 points on the 3MS, indicating no cognitive impairment. The majority of PWDs (51.5%) now showed a moderate level of cognitive impairment and 9.1% were severely impaired.

Table 36: Severity of cognitive impairment at follow-up in comparison with baseline

3MS score	Baseline (<i>n</i> = 52)		Follow-up (<i>n</i> = 33)	
	<i>n</i>	%	<i>n</i>	%
≥ 78	19	36.5	5	15.2
68 – 77	16	30.8	8	24.2
38 – 67	17	32.7	17	51.5
≤ 37	0	0.0	3	9.1

Key. 3MS, Modified Mini-Mental State Examination.

One-way ANOVA revealed that the mean 3MS score for the entire sample dropped significantly ($F_{1,63} = 7.88, p = .007$) by 8.2 points, from 71.1 points at baseline to 63.9 points at follow-up, as can be seen from the data in **Figure 21**. It also shows that the cognition of persons with VD decreased the most with an average of 11.1 points on the 3MS.

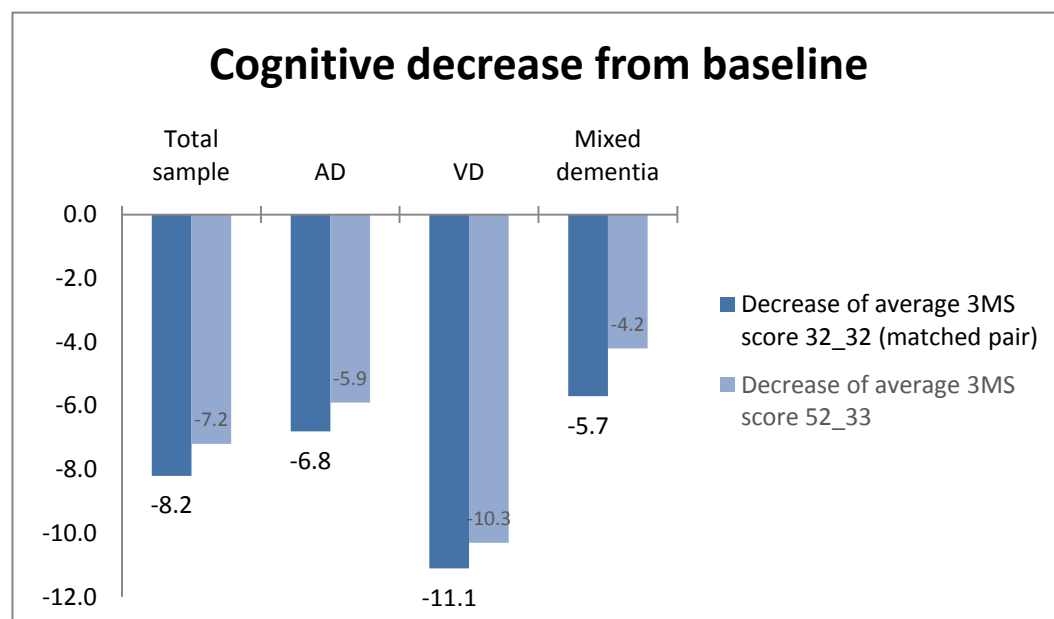


Figure 21: Cognitive change from baseline (mean 3MS scores)

Key. 3MS, Modified Mini-Mental State Examination; AD, Alzheimer's dementia; VD, vascular dementia.

Note. Dark blue bars represent the change between baseline and follow-up based on a matched pair analysis where the data collected from the remaining 33 follow-up participants were matched with the data collected from these 33 participants at baseline ($n = 32$ at t_1 and $n = 32$ at t_2). Light blue bars represent the change between baseline and follow-up based on a non-matched pair analysis ($n = 52$ at t_1 and $n = 33$ at t_2).

Unlike the baseline scores, cognition scores were now significantly negatively correlated with formal care time ($r = -.421, p = .016$). The baseline observations that PWD's cognition decreased

with illness progression ($r = -.740, p < .001$) and lower level of daily functioning ($r = -.488, p \leq .004$) was confirmed.

5.4.1.3 Neuropsychiatric and behavioural symptoms

Matched pair one-way ANOVA analysis revealed that the average total NPI score increased significantly ($F_{1,64} = 5.62, p = .021$) from baseline (9.2 points) to follow-up (16.2 points) with persons with VD exhibiting on average the most and the most severe neuropsychiatric and behavioural symptoms (21.2 points), followed by persons with mixed dementia and AD (Table 34, p. 210). Participants with mixed increased the most on the NPI with an average of 8.6 points and participants with AD the least with an average of 6.3 points (**Figure 22**).

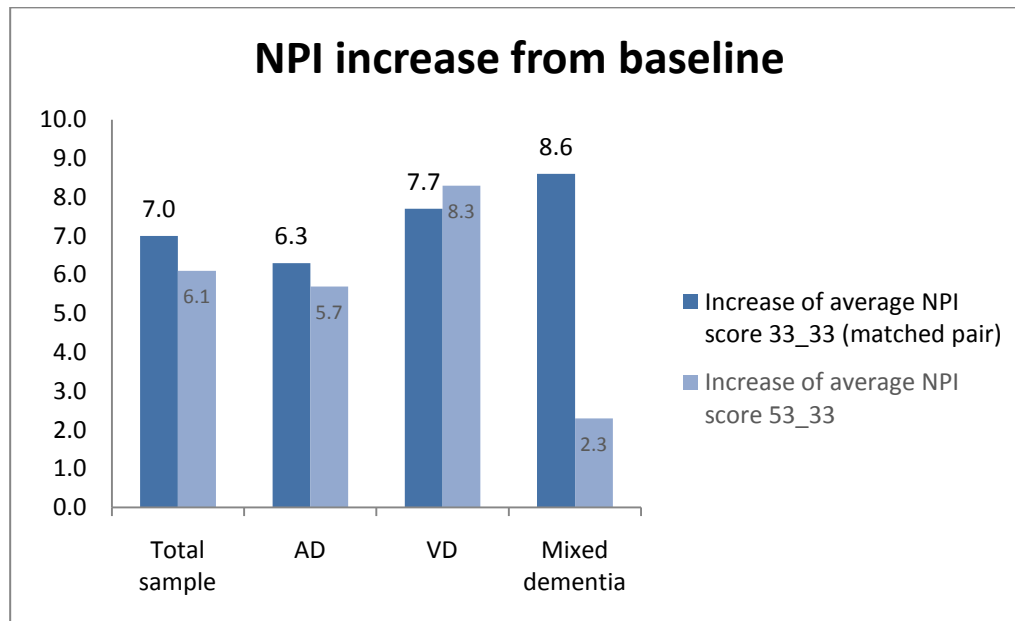


Figure 22: Increase of mean NPI scores from baseline

Key. NPI, Neuropsychiatric Inventory; AD, Alzheimer's dementia; VD, vascular dementia.

Note. Dark blue bars represent the change between baseline and follow-up based on a matched pair analysis where the data collected from the remaining 33 follow-up participants were matched with the data collected from these 33 participants at baseline ($n = 33$ at t_1 and $n = 33$ at t_2). Light blue bars represent the change between baseline and follow-up based on a non-matched pair analysis ($n = 53$ at t_1 and $n = 33$ at t_2).

Figure 23 illustrates that at follow-up, apathy (similar to baseline) and anxiety were the neuropsychiatric and behavioural symptoms observed in the highest percentage of patients. Different to baseline, all neuropsychiatric symptoms (but agitation and hallucination) were observed in a higher percentage of PWDs. This change was statistically significant (matched pair one-way ANOVA) for the following symptoms:

- anxiety ($F_{1,64} = 5.23, p = .026$);
- irritability ($F_{1,64} = 5.49, p = .022$);
- motor behaviour ($F_{1,64} = 4.38, p = .040$).

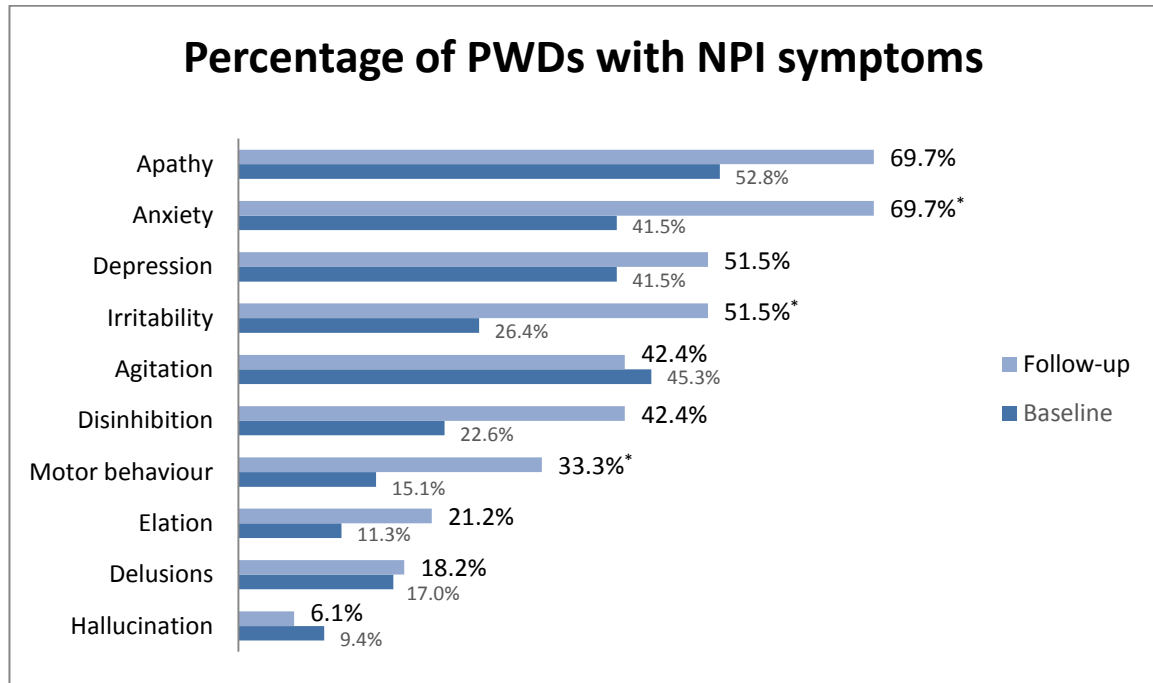


Figure 23: Percentage of PWDs exhibiting NPI symptoms at follow-up compared to baseline

Key. NPI, Neuropsychiatric Inventory.

* $p \leq .050$

More than half of the symptoms increased in terms of their frequency within 1 year as can be seen in **Figure 24**. Amongst those patients who had hallucinations, this symptom was on average the most frequently observed one (almost daily). Very noticeable changes occurred in patients showing elation/euphoria for which the frequency almost doubled within 1 year. Apathy, delusion, depression and disinhibition were less frequently observed in patients with these symptoms compared to baseline (based on matched pair analysis). However, these changes were not statistically significant (one-way ANOVA).

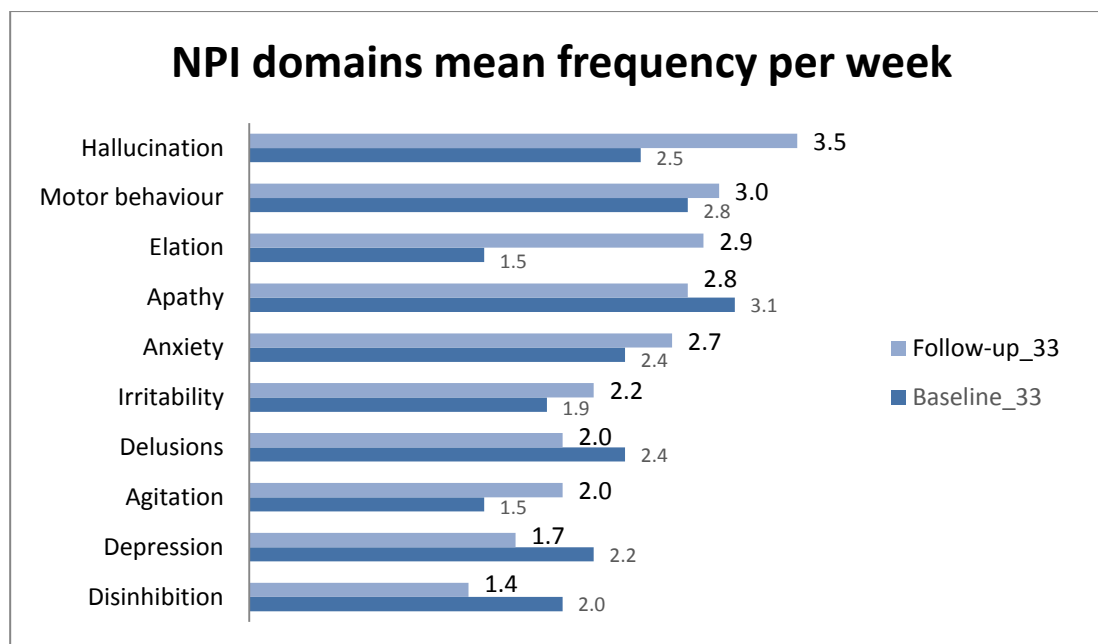


Figure 24: Mean frequency scores of NPI symptoms at follow-up compared to baseline (matched pairs)

Key. NPI; Neuropsychiatric Inventory. Frequency is rated as: 1 – Occasionally: less than once a week; 2 – Often: about once per week; 3 – Frequently: several times per week but less than every day; 4 – Very frequent: daily or essentially continuously present.

The average severity of PWD's neuropsychiatric and behavioural symptoms increased from baseline to follow-up for some symptoms: irritability, agitation/aggression, elation/euphoria and motor behaviour (**Figure 25**). Symptoms of anxiety, depression and apathy decreased in their average severity. However, none of these changes were statistically significant (one-way ANOVA). Hallucinations and/or delusions were two symptoms that did not change between the two assessments.

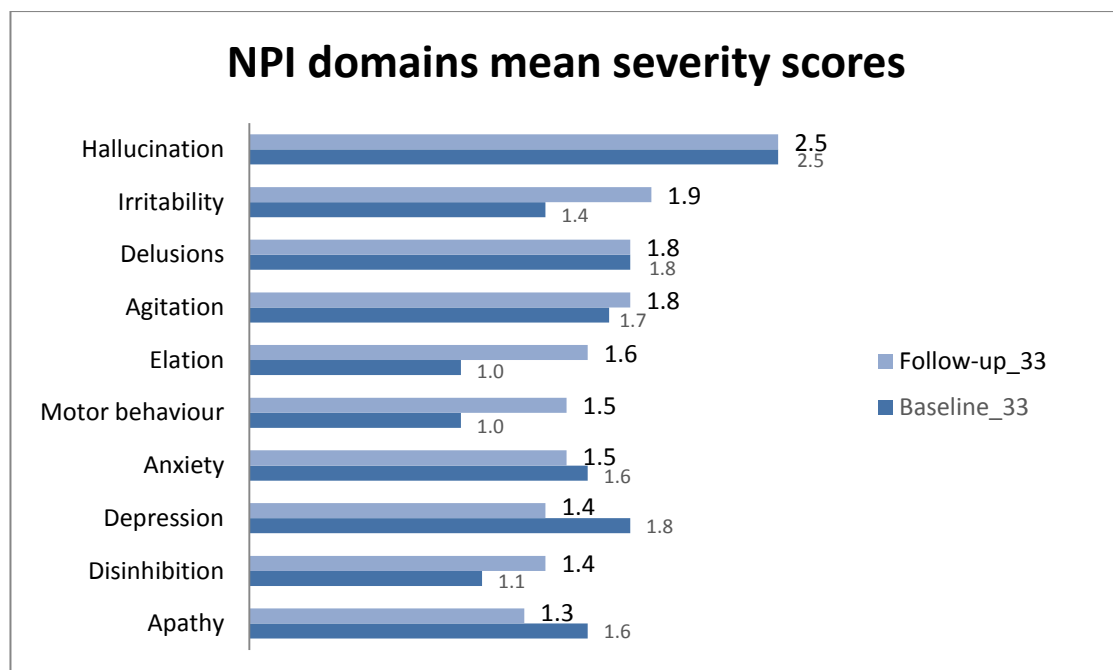


Figure 25: Mean severity scores of NPI symptoms at follow-up compared to baseline (matched pairs)

Key. NPI, Neuropsychiatric Inventory. Severity is rated as: 1 – Mild: produces little distress in the patient; 2 – Moderate: more disturbing to the patient but can be redirected by the caregiver; 3 – Severe: very disturbing to the patient and difficult to redirect.

Overall, average total scores (frequency multiplied by severity) increased for 6 of the 10 symptoms. Symptoms of apathy, delusion, depression and disinhibition decreased as the data from **Figure 26** shows. No statistically significant changes between baseline and follow-up mean NPI scores were observed (one-way ANOVA).

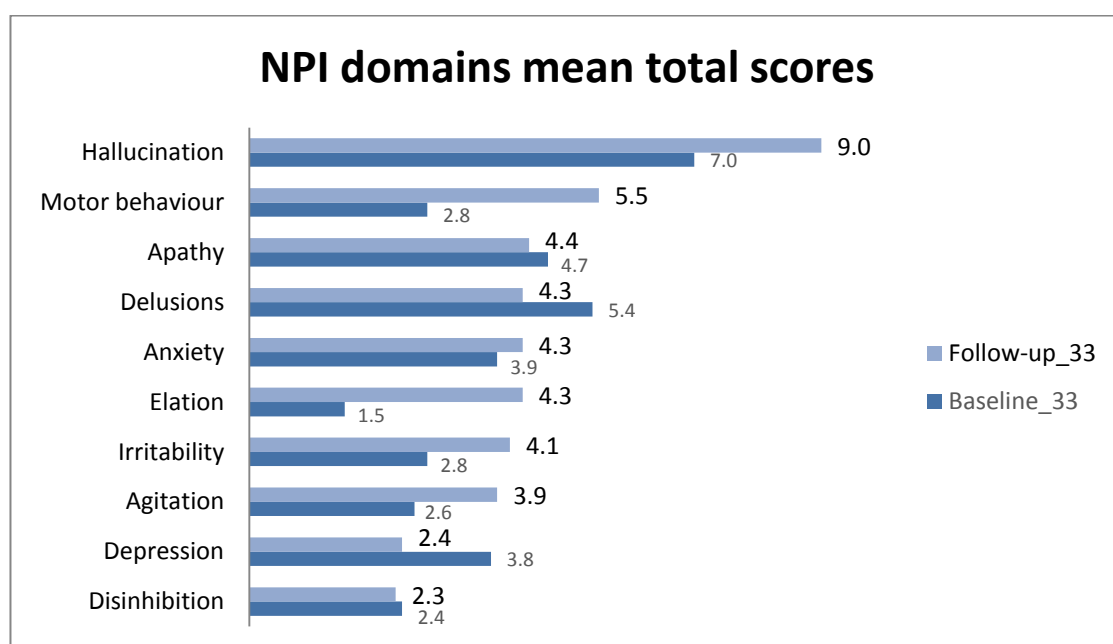


Figure 26: Mean NPI scores (frequency x severity) at follow-up compared to baseline (matched pairs)

Key. NPI, Neuropsychiatric Inventory.

Pearson's correlations were performed for the single NPI items and some of the clinical QoL outcomes. They showed that similar to baseline 'apathy' was one of the two items most often significantly correlated with outcomes such as PWDs' QoL (QOL-ADproxy: $r = -.510, p = .003$) and level of daily functioning (BADLS: $r = .356, p = .045$), and caregivers' burden (BI: $r = .516, p = .002$) and level of informal support (MSPSS: $r = -.495, p = .004$).

Whereas at baseline it was 'disinhibition', at follow-up 'agitation/aggression' was the item that was correlated with more QoL outcomes than any other NPI item: PWDs' QoL (QOL-ADp and proxy: $r = -.376, p = .037$, : $r = -.607, p < .001$ respectively), PWDs' level of depression (CSDD: $r = .492, p = .004$), and caregiver distress (NPI-D: $r = .704, p < .001$) and burden (BI: $r = .478, p = .006$). Interestingly, 'agitation/aggression' was the only item which also significantly correlated with caregivers' level of depression (GDS: $r = .360, p = .043$).

These correlations show that PWDs who presented symptoms of apathy and agitation or aggression had a significantly lower QoL, were more likely to be depressed and functionally more impaired, causing higher levels of burden, distress and depression in their caregivers who at the same time felt less supported by family and friends. The above findings also support the conclusion that apathy was an important QoL predictor because it was the symptom prevalent in the highest percentage of participants (as was anxiety) and one of the most frequently occurring symptoms (several times per week but less than daily). Agitation, however, was more driven by its severity (disturbing for the patient but can be redirected by the caregiver).

The following is a list of Pearson's correlations linked with PWDs' neuropsychiatric and behavioural symptoms (NPI total score) at follow-up:

- PWDs' QoL: proxy ratings ($r = -.585, p < .001$),
- PWDs' depressive symptoms ($r = .523, p = .002$),
- caregivers' level of burden ($r = .644, p < .001$),
- caregivers' level of distress ($r = .764, p < .001$),

- caregivers' level of depression ($r = .387, p = .029$).

The correlation between the total NPI score and caregivers' depression score is new and was not observed at baseline. Also different from baseline scores, PWDs' QoL ratings (QOL-ADp) and caregivers' perceived social support were no longer correlated with patients' total NPI scores. These correlations indicate that PWDs who presented more and more severe neuropsychiatric and behavioural symptoms had a significantly lower QoL (caregiver perspective), were more likely to be depressed and their caregivers showed higher levels of burden, distress and depression than caregivers of PWDs who had a lower NPI score.

5.4.1.4 Daily functioning

As outlined in Table 34 (p. 210), participants diagnosed with VD were on average more severely impaired in their functional abilities (18.5 out of 60 points with more points indicating a more severe level of impairment) than participants with mixed dementia (11.3 points) or AD (8.3 points). **Figure 27** also shows that persons with VD deteriorated the most in their daily functioning with an average increase of 6.6 points on the BADLS. The average increase for the total follow-up sample was 5.7 points which was statistically significant at the $p = .009$ level using one-way ANOVA matched pair testing ($F_{1,64} = 7.31$).

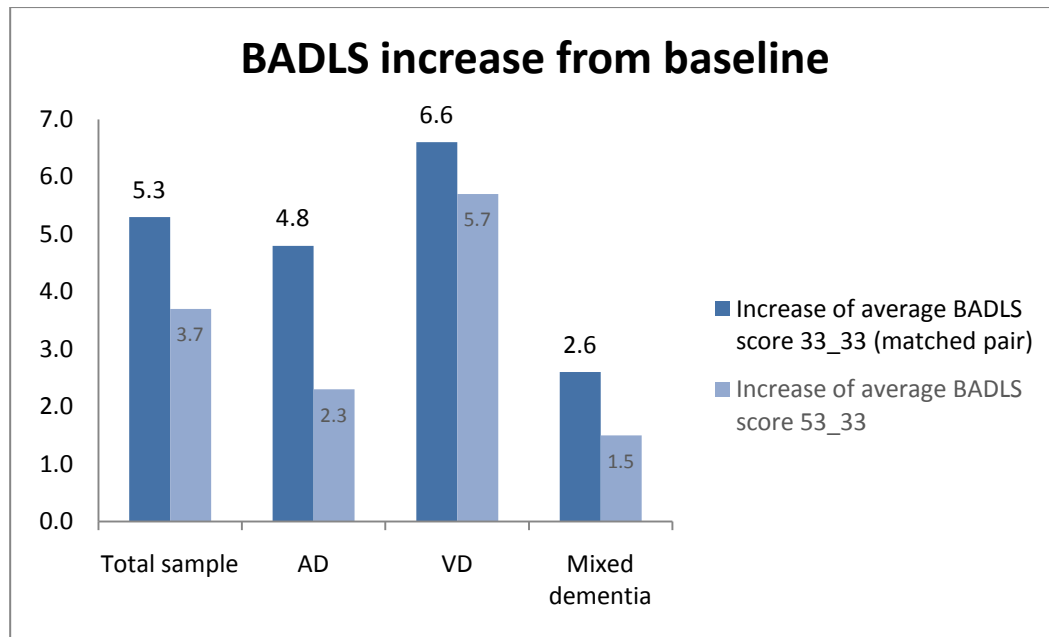


Figure 27: Increase of average BADLS score from baseline

Key. BADLS, Bristol Activities of Daily Living Scale; AD, Alzheimer's dementia; VD, vascular dementia.

Note. Dark blue bars represent the change between baseline and follow-up based on a matched pair analysis where the data collected from the remaining 33 follow-up participants were matched with the data collected from these 33 participants at baseline ($n = 33$ at t_1 and $n = 33$ at t_2). Light blue bars represent the change between baseline and follow-up based on a non-matched pair analysis ($n = 53$ at t_1 and $n = 33$ at t_2).

The data in **Figure 28** illustrate that at follow-up almost every PWD had some difficulties with temporal (93.9%) and geographic orientation (87.9%). Every second PWD was not able to communicate (48.5%) and to get dressed (45.5%) as easily as before having dementia. Almost one in three patients needed assistance to bath or shower (27.3%). The relative ratings were almost maintained between baseline and follow-up. However, unlike at baseline, impairments in all aspects of basic daily functioning (but mobility) were observed in a higher percentage of PWDs. The increase of impairment of ADLs was statistically significant (matched pair one-way ANOVA) for the following factors:

- orientation - time ($F_{1,64} = 8.53, p = .006$);
- orientation - space ($F_{1,64} = 25.13, p < .001$);
- communication ($F_{1,64} = 5.71, p = .020$);
- dressing ($F_{1,64} = 12.80, p = .001$);
- total ADL score ($F_{1,64} = 9.89, p = .003$).

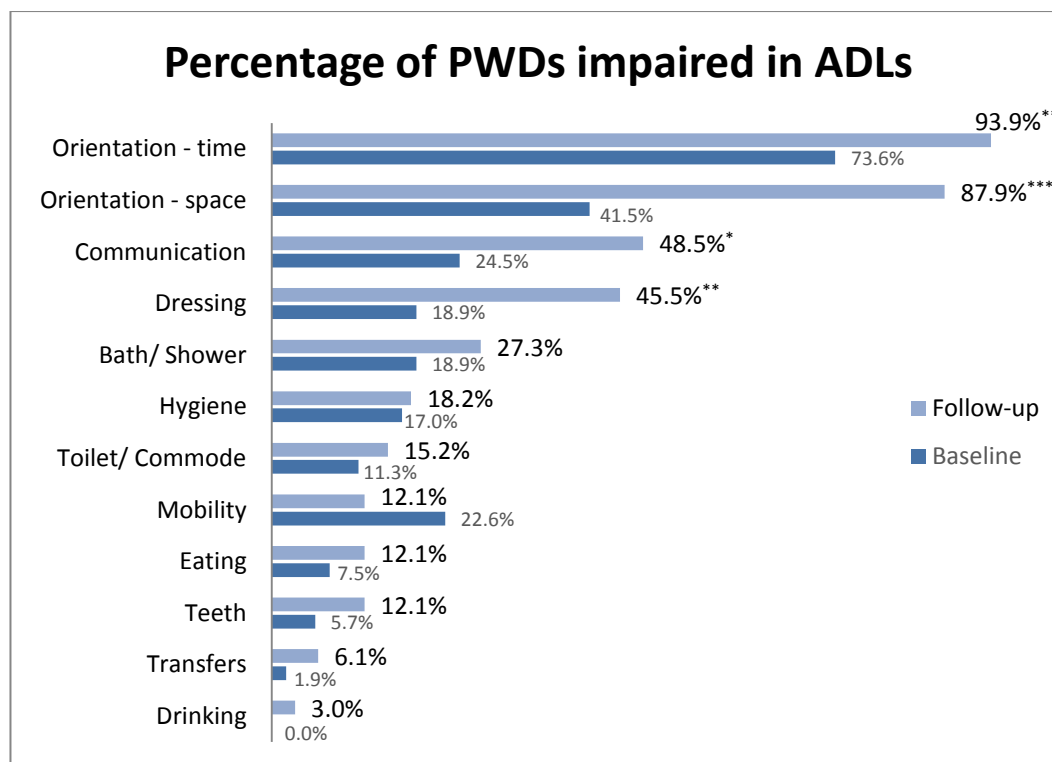


Figure 28: Percentage of PWDs with ADL impairments at follow-up compared to baseline

Key. PWDs, persons with dementia; ADLs, basic activities of daily living.

*** $p \leq .001$, ** $p \leq .010$, * $p \leq .050$

Figure 29 shows that all ADLs were more impaired at follow-up as compared to baseline (matched pairs). Over time, patients' geographic orientation ($F_{1,64} = 10.68$, $p = .002$) and their ability to communicate ($F_{1,64} = 5.14$, $p = .027$) and to dress themselves ($F_{1,64} = 12.64$, $p = .001$) worsened more than other ADLs (one-way ANOVA).

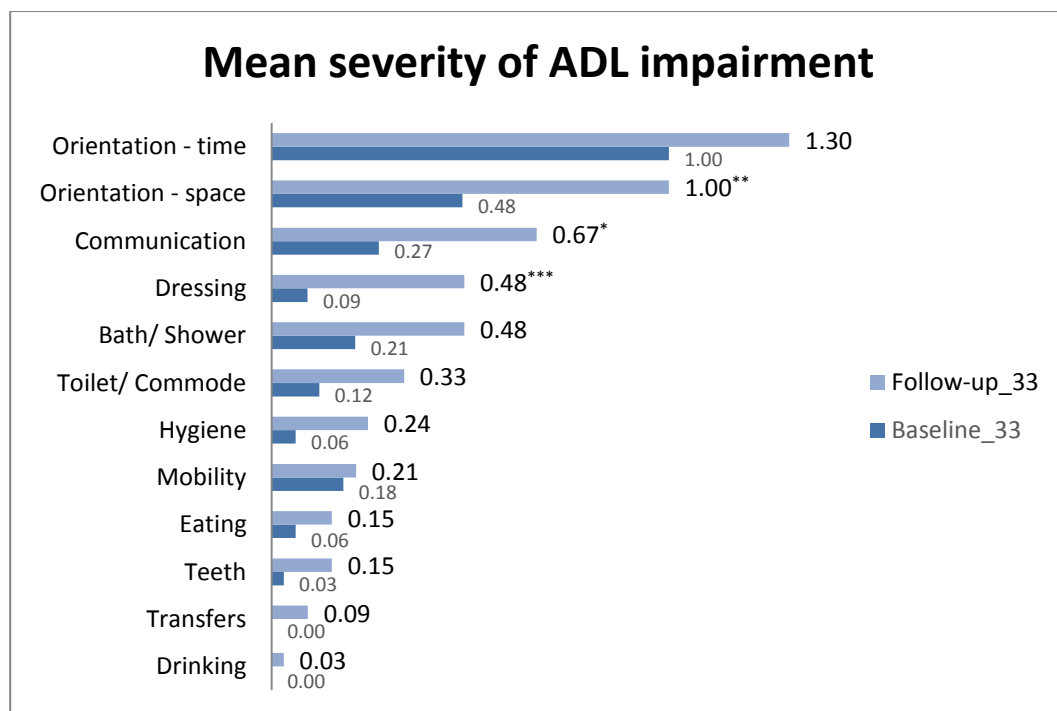


Figure 29: Mean severity scores of ADL impairments at follow-up compared to baseline (matched pairs)

Key. ADL, basic activity of daily living.

Note. Orientation space: change significant ($F_{1,64} = 10.68, p = .002$); Communication: change significant ($F_{1,64} = 5.14, p = .027$); Dressing: change significant ($F_{1,64} = 12.64, p = .001$).

*** $p \leq .001$, ** $p \leq .010$, * $p \leq .050$

Figure 30 illustrates that all instrumental activities of daily living except the ability to prepare food (a sandwich) were impaired in a higher percentage of patients at follow-up as compared to baseline. More than two thirds of patients had difficulties with shopping (72.7%) and financial matters (66.7%). The relative ratings changed between baseline and follow-up. The increase of impairment of IADLs was statistically significant (one-way ANOVA) for the following factors:

- shopping ($F_{1,64} = 9.85, p = .003$);
- finances ($F_{1,64} = 4.03, p = .049$);
- games/ hobbies ($F_{1,64} = 4.03, p = .049$).

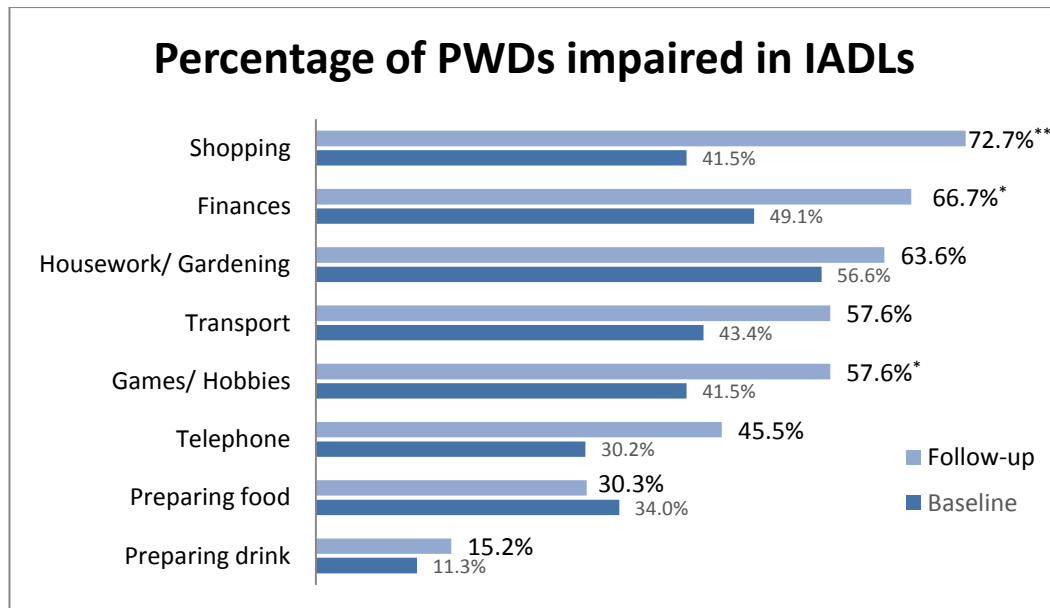


Figure 30: Percentage of PWDs with IADL impairment at follow-up compared to baseline

Key. PWDs, persons with dementia; IADLs, instrumental activities of daily living.

** $p \leq .010$, * $p \leq .050$

Figure 31 demonstrates that all IADLs, except the ability to prepare something to eat, were more impaired at follow-up than they were 12 months earlier (matched pairs). PWDs' ability to help around the house and garden was rated as being most impaired at baseline. One-way ANOVA showed that over time, patients' ability to do some shopping and to handle financial matters became on average significantly more impaired ($F_{1,64} = 7.00$, $p = .010$; $F_{1,64} = 6.04$, $p = .017$ respectively).

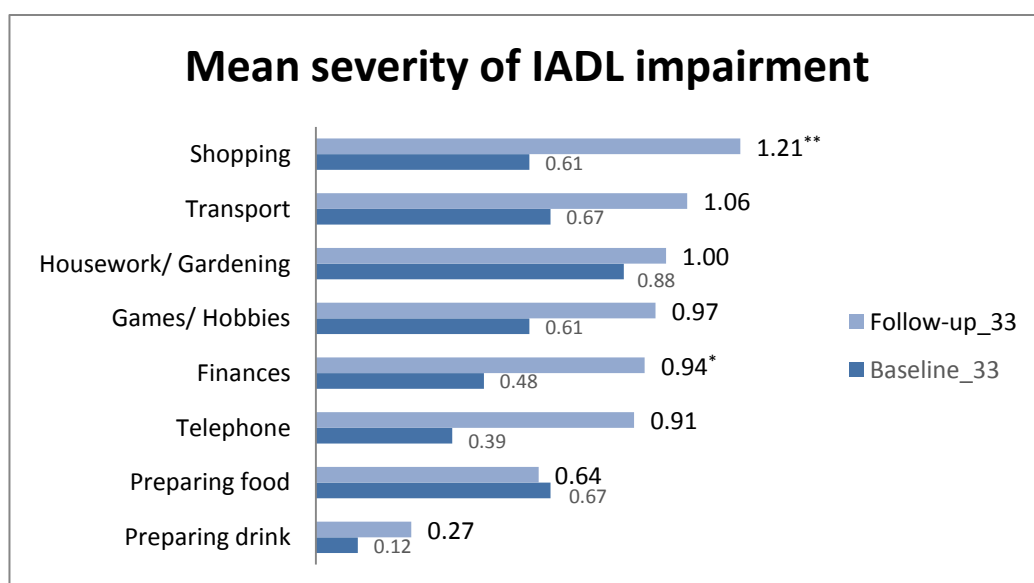


Figure 31: Mean severity scores of IADL impairments at follow-up compared to baseline (matched pairs)

Key. IADL, instrumental activity of daily living.

Note. Shopping: change significant ($F_{1,64} = 7.00$, $p = .010$); Finances: change significant ($F_{1,64} = 6.04$, $p = .017$)

** $p \leq .010$, * $p \leq .050$

5.4.2 Clinical measures of caregiver quality of life

No statistically significant differences between baseline and follow-up assessments were found for caregivers' QoL outcomes. However, one-way ANOVA analysis showed that caregivers' level of distress increased but failed to reach statistical significance ($F_{1,64} = 3.62, p = .062$). This suggests that the increasing prevalence of neuropsychiatric and behavioural symptoms in patients leads to an increasing level of distress in their caregivers as a reaction towards these symptoms.

In conclusion, these findings show that 12 months is not enough time to observe differences in caregiver outcomes. However, it was found that the stage of dementia significantly progressed, that patients' level of cognitive and functional impairment significantly deteriorated and that neuropsychiatric and behavioural symptoms significantly increased between baseline and follow-up. **The hypothesis that similar QoL predictors can be observed over time (12 months) but their clinical values might deteriorate was therefore supported.**

5.5 Caregivers' coping ability: some qualitative data

Using a questionnaire, developed for this purpose, some data were collected regarding caregivers' coping during the past 12 months at follow-up. It was expected that there would be times during the 12 months between baseline and follow-up assessment when caregivers would struggle more and others when they would have fewer difficulties coping with their relatives' illness (as listed under point 1.c of chapter 3.3, p. 114). Information was obtained from the sample of 33 caregivers who completed the follow-up assessment and from a further 10 caregivers who provided information after their relatives had moved into residential care.

About 2 in 3 participants (62.8%, $n = 27$) said that there was a period in the 12 months prior to follow-up assessment that was very difficult for them. In the case of the caregivers whose relative had been admitted into permanent care, the question related to the months prior to this change. Caregivers were also asked which months were the ones when they struggled the most to care for the PWD and, using an open question, what reasons made these particular months the worst

period. These causes for caregivers' decreased coping abilities were grouped and are presented in **Table 37.**

Table 37: Reasons for caregivers' decreased coping ability

Reason	Examples
Acceptance diagnosis, insight, denial	<ul style="list-style-type: none"> → no driving → grief over diagnosis → fear of loss of independence felt by PWD → no insight of PWD into condition even though dementia quickly worsening → PWD would not accept to go into respite care while caregiver went away on holidays
Loss of spousal relationship between PWD and caregiver	<ul style="list-style-type: none"> → feels left alone by PWD → loss of friendship and sharing
Decreasing cognition	<ul style="list-style-type: none"> → extreme worsening of PWD's cognition within the year → cognitive decline → increasing memory difficulties → spending money on cake, but not eating at home despite diabetes → difficulty to adopt to new environment after moving into new place
Decreasing ADL/IADL of PWD	<ul style="list-style-type: none"> → no domestic help from PWD → inability to do any cooking or only very limited housework → deterioration of PWD's functioning (after relative passed away) → personal hygiene → wearing dirty cloths and putting them back in wardrobe
Increasing neuropsychiatric and behavioural symptoms	<ul style="list-style-type: none"> → winter: PWD reluctant to get up in morning → wandering off home every night → increasing confusion
Burden of care	<ul style="list-style-type: none"> → visiting PWD every day in hospital (hospital level care) → feeling guilty about decision to change PWD into permanent care → constant phone calls from PWD → Unaware at the time how difficult the coping process was. Quality of job suffered. Caregiver realised how demanding care role must have been during that time. → caregivers health (arthritis) got worse because of care burden and the other way around
PWD physical health	<ul style="list-style-type: none"> → incontinence → hospitalisations → falls → depression → comorbidities such as cancer, strokes, ulcers → problems with mobility → PWD damaged back and had to use walking frame, became "despondent"
PWD mental health	<ul style="list-style-type: none"> → winter: PWD reluctant to get up in morning → depressive symptoms stronger during winter months → PWD seemed to "just give up"

Table 37: Reasons for caregivers' decreased coping ability (continued)

Reason	Examples
Caregiver physical health	<ul style="list-style-type: none"> → hospitalisation → dialysis → heart attack → chronic blood ischemia → stroke of caregiver who had to be cared for by PWD
Caregiver mental health	<ul style="list-style-type: none"> → feeling more depressed during Christmas because 'time of outing' → depression after diagnosis of PWD
Lack of formal support	<ul style="list-style-type: none"> → no respite for PWD available at the time carer was in hospital → no permanent care place available when needed → lack of professionalism in residential care facilities with dementia units
Lack of informal support	<ul style="list-style-type: none"> → no support from family → no uniformity amongst between care and other family members
Others	<ul style="list-style-type: none"> → grief over relatives passing

Key. PWD(s), person(s) with dementia

Almost every second caregiver (41.9%, $n = 18$) agreed that there was a period during these 12 months that was easier for them. Caregivers were also asked which months were easier and, using an open question, what reasons made these particular months easier than other ones. The only positive comments were regarding changes after medication had been prescribed.

In the first case, the PWD had a number of minor strokes "but when put on Warfarin (blood thinner) things became much easier" because it was possible to communicate with the patient who also seemed more energetic. In the second case, the caregiver noticed a positive change in the PWD after Exelon was started.

The hypothesis that the coping abilities and process would vary during the 12 months was supported. More caregivers experienced difficult times than easier periods.

5.6 Discontinuing participants and admittance into permanent care

Twenty participants ($n = 20$) were lost to follow-up. The main reason for discontinuation was the admission of the PWD into permanent care ($n = 12$), as **Table 38** shows. This happened on average

about 6 months after the baseline interview. Three patients and 3 caregivers died, on average 4 months after the initial assessment. Other reasons for discontinuation were withdrawal at the wish of the caregiver and short term care placement (respite) of the PWD at the due time of the follow-up assessment.

Table 38: Reasons for discontinuation of study participation

Reason for discontinuation	<i>n</i> (<i>n</i> =20)	Average time in study (months)
Death of person with dementia	3	4.0
Admittance into permanent care	12	5.6
Death of caregiver	3	3.7
Other	2	12.0

Looking at Pearson's correlations, to be lost to follow-up was only predicted by the overall baseline-BADLS score ($r = .278, p = .044$) but more significantly by the ADL score as part of the BADLS ($r = .426, p = .001$). This clearly shows that a more severe level of impairment of PWDs' ability to perform basic activities of daily living predicts a more likely admission into permanent care. Potential baseline-predictors were furthermore PWDs' decreasing health status (proxy rated: $r = .269, p = .051$) and increasing dementia progression (CDR: $r = .264, p = .056$). However, both outcomes only approached statistical significance.

Similar predictors (baseline-measures) for discontinuation of participation in the study were found using a one-way ANOVA analysis: an increased BADLS score ($F_{1,51} = 4.28, p = .044$) and an increased number ($F_{1,50} = 5.92, p = .019$) and length of formal care contacts ($F_{1,51} = 11.13, p = .002$). Almost statistically significant were PWDs' decreasing health status (proxy rated: ($F_{1,51} = 3.98, p = .051$), the progressing stage of dementia (CDR: $F_{1,51} = 3.82, p = .056$) and patients' self rated decreasing QoL (QOL-ADp: $F_{1,51} = 3.51, p = .067$).

Surprisingly, outcomes such as pathology (VD possibly increased risk for stroke), income (being more able to afford permanent care), relationship (children more distanced and therefore likely to

admit PWD into permanent care than spouses) or caregiver depression were not significantly correlated with admission into permanent care.

Data were collected from 10 of the 12 caregivers whose relatives were now living in permanent care. Two questionnaires were not returned. The data in **Figure 32** shows that half the PWDs moved into a dementia-specific residential care home (50%), followed by an almost equal number of patients who moved into a non-dementia specific care facility and one person who required hospital level care due to a stroke with sudden deterioration of his health.

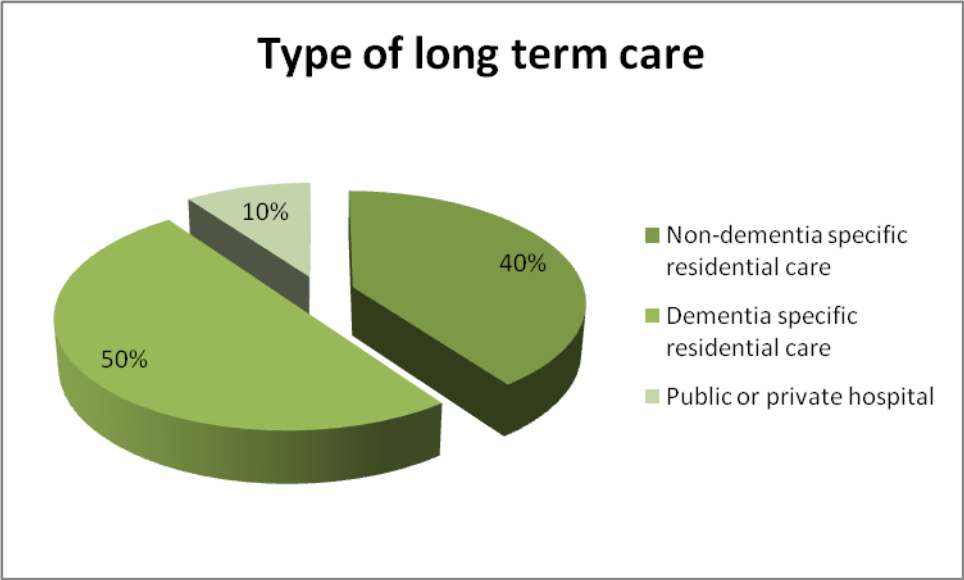


Figure 32: Type of long term residential care of discontinuing PWDs

A number of reasons led caregivers to the decision to admit the PWDs into permanent care. Patients’ worsening cognition was the reason which influenced this decision most often as can be seen from the data in **Figure 33**. Similarly, for a majority of caregivers (60%), patients’ worsening ability to perform daily tasks was also a primary reason for residential care.

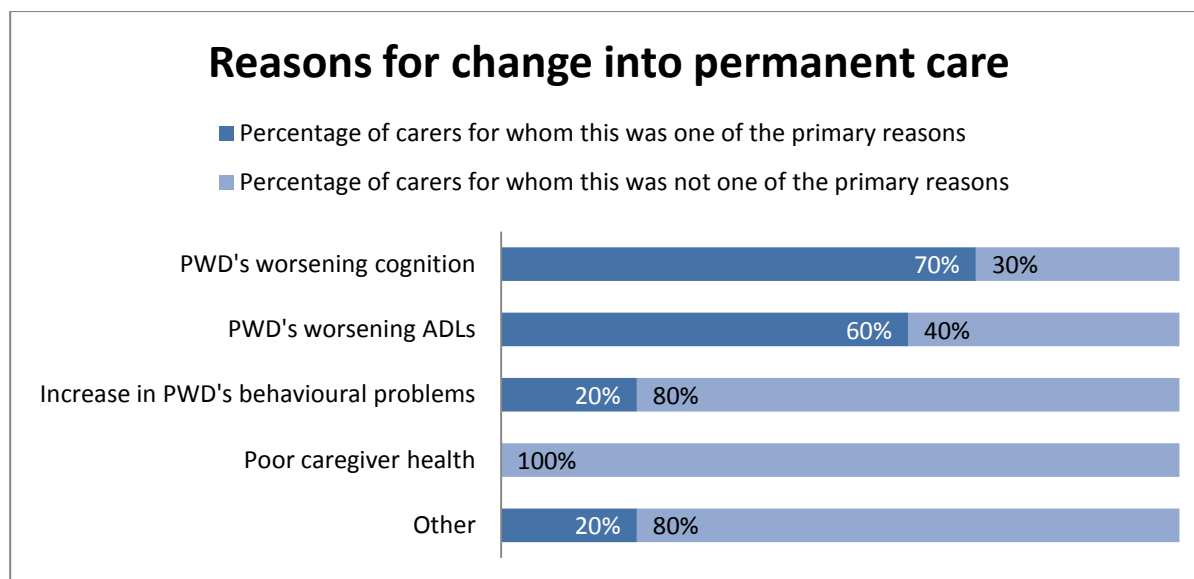


Figure 33: Reasons for change into permanent care

Key. PWD's, person's with dementia; ADLs, activities of daily living.

Note. It was possible to indicate more than one reason.

Unlike a recent study where PWDs' behavioural disturbances were the main reason for change into permanent care (Schoenmakers, Buntinx, Devroey, Van Casteren, & DeLepeleire, 2009), in this current study patients' increasing behavioural problems were less often the reason for the change in living accommodation (20%). None of the caregivers considered their own health to be the main reason for this decision.

5.7 Formal interventions in New Zealand (Canterbury)

The second research objective was to examine what interventions (treatment benefit) from primary and secondary care in New Zealand are helpful for enhancing QoL. A treatment benefit was assumed if medical and/or educational and/or psychological and/ or social support were utilised by PWDs and/or their caregivers. The group of participants that utilised a certain type of support was therefore compared to the group of participants who did not use the support in terms of their QoL outcomes. The question was if these outcomes remained more stable or improved more significantly from baseline to follow-up in those participants who took advantage of available supports and interventions as compared to those who did not.

The results of the following section relate to the hypotheses as listed under point 2.a of chapter 3.3 (p. 114):

- The utilisation of medical and/or educational and/or psychological and/ or social supports and interventions will improve PWDs' and caregivers' QoL over time.
- Some QoL outcomes will worsen between baseline and follow-up despite the utilisation of supports and interventions.
- Taking advantage of available support options will result in fewer negative changes.

Some additional, very specific hypotheses are listed within the appropriate sections. All sections start with some descriptive analyses followed by an evaluation to determine each intervention's probability to sustain or improve participants' QoL. Matched pair one-way ANOVA was used to determine differences in formal care utilisations between baseline and follow-up based on the entire sample of dyads completing the assessment process ($n = 32$). Only the utilisation of dementia medication (5.7.2.1, p. 234) and day care use (5.7.4.1, p. 257) changed significantly. However, descriptive analyses showed differences between participants utilising an intervention at baseline and those utilising a support at follow-up. It has to be noted that the analyses of hypothesised benefits of formal services was based on a small number of subjects who completed the 12-month assessment ($n = 32$), and many of the services included were used only briefly or only by an even smaller number of participants. Thus, this part of the analysis is somewhat speculative and should be understood as exploratory.

5.7.1 Early diagnosis and intervention

In order to verify the hypothesis (as listed under point 2.b of chapter 3.3, p. 114) that early diagnosis and intervention can improve PWDs' QoL and decrease behavioural symptoms, a number of analyses were performed. Early diagnosis in this study was translated into a diagnosis made at an early stage. Since patients' stage of illness had been measured using the CDR, this score functioned as a dependent variable.

First, one-way ANOVA was used to determine if there was any difference between patients' who had a lower CDR score (0.5 or 1) at baseline and patients with a higher CDR score (2) regarding their clinical QoL outcomes at follow-up. The results are presented in **Table 39**.

Table 39: One-way ANOVA: differences between patients with mild and those with moderate dementia (CDR baseline) regarding their QoL outcomes at follow-up

	CDR 0.5 (mean ± SE)	CDR 1.0 (mean ± SE)	CDR 2.0 (mean ± SE)	$F_{2,29}$	p
	$n = 15$	$n = 14$	$n = 3$		
QOL-ADp	42.20 ± 0.71	40.38 ± 1.85	34.33 ± 0.88	3.40 ¹	.047
QOL-AD proxy	37.73 ± 0.96	34.21 ± 1.02	32.33 ± 1.76	4.56	.019
NPI	12.13 ± 2.33	22.86 ± 3.99	10.33 ± 3.18	3.42	.047
BADLS	8.13 ± 1.32	12.50 ± 1.74	26.67 ± 9.39	8.72	.001
BI	18.40 ± 3.80	28.93 ± 3.03	12.00 ± 5.13	3.46	.045

Key. CDR, Clinical Dementia Rating Scale; QOL-ADp, Quality of Life-Alzheimer Disease Scale patient rating; QOL-ADproxy, Quality of Life-Alzheimer Disease Scale proxy rating; NPI, Neuropsychiatric Inventory; BADLS, Bristol Activities of Daily Living Scale; BI, Zarit Burden Interview.

¹ $F_{2,28}$

It was found that PWDs with a lower CDR score at baseline had better QoL ratings at follow-up (patient and caregiver perspective) and were functionally less impaired. Patients with a CDR score of 0.5 at baseline, the lowest CDR score, also had significantly fewer neuropsychiatric and behavioural symptoms at follow-up than patients with a CDR of 1.0. But patients with a high CDR score of 2.0 at baseline seemed to have decreased in their NPI symptoms at follow-up (**Table 39**). However, these data are based on only 3 patients at follow-up. Also, it is more likely that PWDs with more (severe) NPI symptoms had discontinued the study and it is less likely that these symptoms decreased during the more severe stages of dementia. Considering further, that (as shown before [p. 209]) ratings of PWDs' QoL did not change significantly between baseline and follow-up, **the hypothesis that early diagnosis can improve PWDs' QoL, was not supported.**

The hypothesis that early diagnosis can decrease patients' neuropsychiatric and behavioural symptoms could not be determined. Linear regression analysis found no significant relationship between patients' baseline CDR score and patients' baseline and follow-up NPI scores. However,

even if patients' neuropsychiatric and behavioural symptoms did not decrease when they had been diagnosed earlier in their illness progression (CDR score of 0.5), the data above still shows that those patients had 1 year after diagnosis a 46.9% lower NPI score than patients who were only diagnosed at a more advanced stage of dementia (CDR score of 1.0).

Second, a two-way ANOVA was used to find out if there were any significant differences regarding the other QoL outcomes between patients who had a lower CDR score at baseline and who had and had not utilised any of the available interventions during the year and those patients who had a higher CDR score at baseline and who had or had not utilised any intervention. The analysis showed that there were not enough data available to determine group differences. **The hypothesis that early intervention can improve PWDs' QoL could therefore not be determined.**

5.7.2 Medical and domestic supports/interventions

Medical and domestic supports and interventions were analysed for the PWDs as well as for their caregivers and included dementia and mental health medication, professional out-of-home care and professional in-home care. These findings relate specifically to the hypothesis (point 2.f of chapter 3.3, p. 114) that higher levels of caregiver stress can cause an increase in the use of medical services.

One-way ANOVA showed that the utilisation of medical supports and interventions did not differ in PWDs depending on whether PWDs were holding a community services card or not. However, differences were observed in caregivers depending on whether they had a community services card or not. A trend was observed that caregivers with a community services card were more likely to have seen a medical professional ($F_{1,50} = 3.21, p = .079$), to have been hospitalised ($F_{1,50} = 3.88, p = .054$) and to have been taking mental health medication ($F_{1,50} = 3.12, p = .083$) within the 3 months prior to the baseline assessment than non-card holders. Interestingly, caregivers with a community services card also rated their QoL (QOL-ADc) significantly lower ($F_{1,50} = 6.70, p = .013$). However, further analysis showed that these utilisation differences were not income related.

5.7.2.1 Medication

The data presented in the **Table 40** were collected with the Service Use Questionnaire. They show that about one in three patients were taking one of the three ChEIs or Memantine at baseline and slightly more at follow-up. An additional 15.1% at baseline and 9.1% 1 year later also took other mental health medication such as anti-depressants (including Fluoxetine, Paroxetine, Citalopram), anti-psychotics (such as Haloperidol), anti-anxiety medication (including Clonazepam, Lorazepam), bipolar medication (such as Tegretol, Quetiapine) and sleep medication (Zopiclone, Temazepam, Rubifen). The number of PWDs who took only mental-health medications decreased notably between baseline (26.4%) and follow-up (18.2%). At the same time, the percentage of patients who took none of the above medications increased from 25% to 36%. Using one-way ANOVA, it was found that this increase was statistically significant ($F_{1,62} = 4.15$, $p = .046$). The opposite was observed for caregivers where the percentage of participants using mental health medication increased from 15% at baseline to 21% at follow-up.

Table 40: Medication utilisation of patients and caregivers at baseline and follow-up (questionnaire and diary data)

		Patient		Caregiver	
		Baseline (<i>n</i> = 53)	Follow-up (<i>n</i> = 33)	Baseline (<i>n</i> = 53)	Follow-up (<i>n</i> = 33)
Patients who utilised dementia medication (ChEIs, Memantine)	<i>n</i>	18	12	n. a.	n. a.
	%	34.0	36.4	n. a.	n. a.
Participants who utilised mental health medication	<i>n</i>	14	6	8	7
	%	26.4	18.2	15.1	21.2
Patients who utilised ChEIs and mental health medication	<i>n</i>	8	3	n. a.	n. a.
	%	15.1	9.1	n. a.	n. a.
Participants who utilised no medication	<i>n</i>	13	12	45	26
	%	24.5	36.4	84.9	78.8

Key. ChEIs, Cholinesterase inhibitors.

Note. Data are based on utilisation at time of assessment.

Two-way ANOVA analysis showed no difference between PWDs who utilised dementia medication and those who did not between baseline and follow-up. However, a trend was observed for a

different NPI score between both groups ($F_{1,55} = 2.23, p = .141$). The NPI score increased less for the PWDs who took either ChEIs or Memantine as compared to those who did not.

The following analysis will show if there were any differences between those patients who utilised a dementia medication already at baseline and those who did not regarding their neuropsychiatric and behavioural symptoms. PWDs who did not utilise ChEIs or Memantine had the highest average NPI scores (frequency x severity) for the items ‘aberrant motor behaviour’, ‘apathy’ and ‘disinhibition’ at baseline as **Figure 34** shows. At follow-up, the average ‘hallucination’ score had increased from 2.7 to 12.0, resulting in the highest average item score followed by ‘aberrant motor behaviour’ and ‘elation/euphoria’ (**Figure 34**).

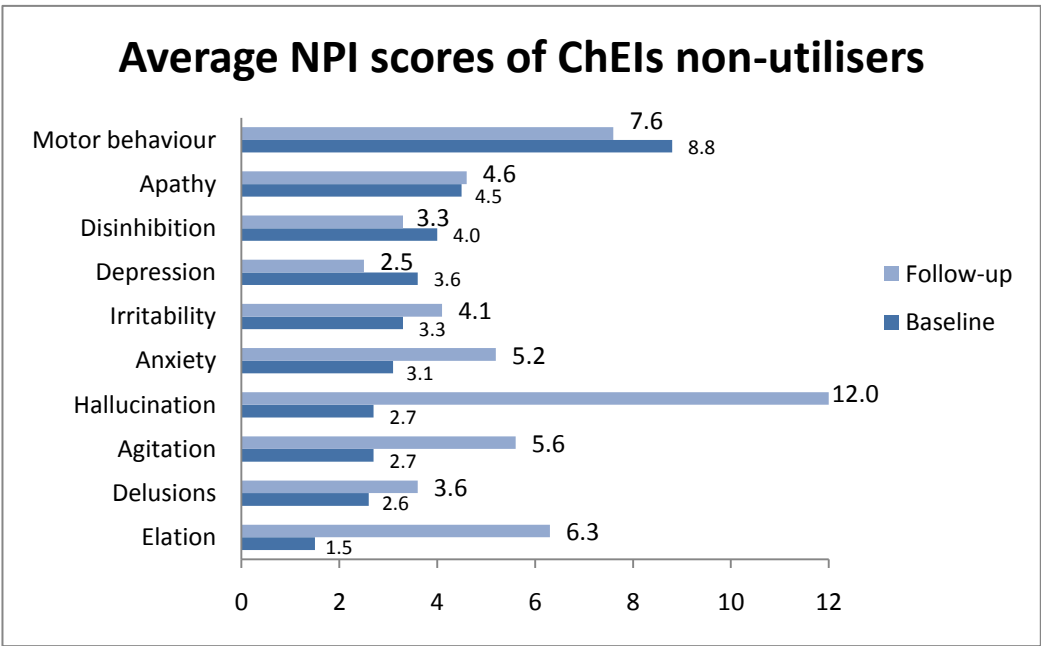


Figure 34: Average NPI item scores at baseline and follow-up for patients who did not utilise dementia medication (ChEIs/Memantine)

In contrast, PWDs who utilised ChEIs/Memantine had the highest average scores for the items ‘delusions’ and ‘hallucinations’ both at baseline and follow-up. Both outcomes improved until follow-up (**Figure 35**).

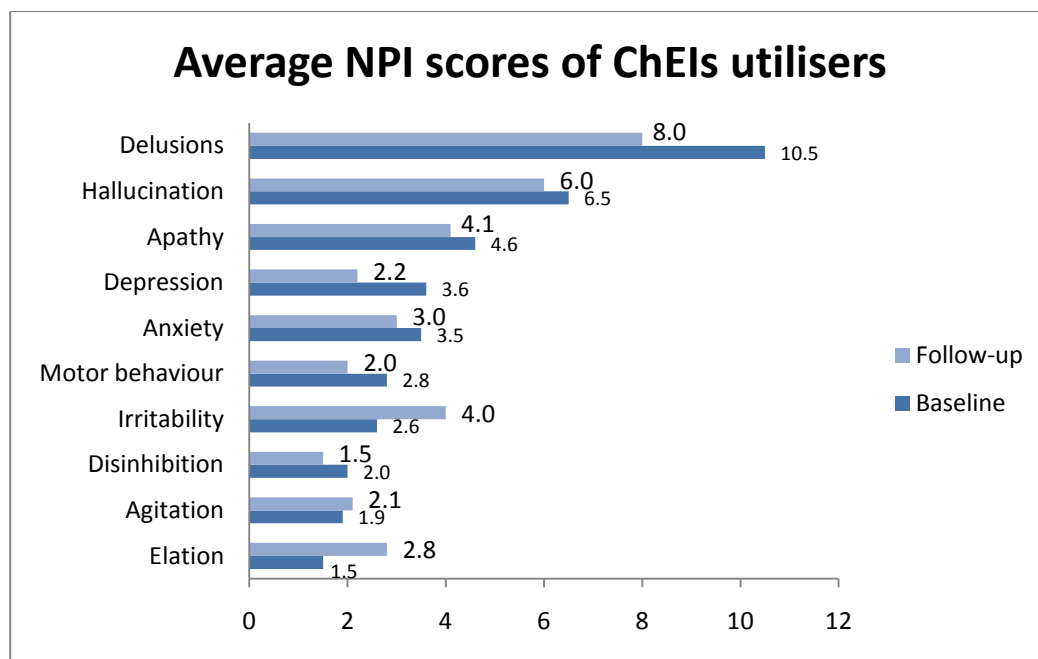


Figure 35: Average NPI item scores at baseline and follow-up for patients who utilised dementia medication (ChEIs/Memantine)

Based on these findings it appears that PWDs who showed increased psychosis symptoms already at baseline were more likely to utilise dementia medication which seemed to have a positive effect on those symptoms in particular. A positive impact of dementia medications on patients' neuropsychiatric and behavioural symptoms was therefore somewhat to be expected.

The following results relate to the hypothesis as listed under point 2.c of chapter 3.3, p. 114: ChEIs might have a positive impact on patients' cognitive and daily functioning, particularly in mild to moderate dementia. To verify this hypothesis, patients who took ChEIs or Memantine were compared to those who did not utilise any of these medications regarding their 3MS scores as well as their BADLS scores at follow-up using one-way ANOVA analysis. No significant difference was observed for any of the QoL clinical outcomes, including the 3MS and BADLS scores. Using Pearson's correlation no significant association was found at follow-up regarding the utilisation of dementia medication. **The hypothesis that ChEIs might have a positive impact on patients' cognitive and daily functioning, particularly in mild to moderate dementia was not supported.** However, there were indications that ChEIs might have a positive impact on patients' neuropsychiatric and behavioural symptoms.

A two-way ANOVA analysis showed no differences between patients who took some mental health medication and those who did not during the 3 months prior to baseline and follow-up assessment. One-way ANOVA analysis showed that patients who were using mental health medication such as anti-depressants within the 3 months prior to follow-up rated their QoL lower ($F_{1,29} = 6.46, p = .017$) received lower QoL ratings from their caregivers ($F_{1,30} = 7.49, p = .010$) and had higher depression ($F_{1,30} = 11.83, p = .002$) and NPI scores ($F_{1,30} = 9.05, p = .005$). It is not surprising that patients who have been prescribed mental health medications were more likely to be depressed and show neuropsychiatric and behavioural symptoms. These findings were confirmed using Pearson's correlation analysis. Additionally, it was also found that caregivers of these patients rated the patient's health status lower (Comorbidities proxy: $r = -.357, p = .045$) and they felt more burdened (BI: $r = -.397, p = .024$) and distressed (NPI-D: $r = -.438, p = .012$) than other caregivers.

No significant differences were observed for the group of caregivers using mental health medication and those who did not use any mental health medication during the 3 months prior to baseline and follow-up assessment (two-way ANOVA analysis). However, at follow-up caregivers' distress scores (NPI-D) were higher for those utilising the medication at a $p = .034$ level (one-way ANOVA: $F_{1,30} = 4.96$) which was also confirmed using Pearson's correlation. There was also a trend that these caregivers rated their QoL lower ($F_{1,30} = 3.79, p = .061$).

5.7.2.2 Professional out-of-home care

The data presented in **Table 41** were collected via the Service Use Questionnaire as well as the diaries which caregivers had been asked to fill in for 1 year regarding their own and the patients' health care utilisation. Data were only compared between questionnaire and diary for follow-up and the fourth quartile respectively, since the questionnaire data were based on the 3 months prior to interview. The diary, however, was only started after the baseline interview and not prior to it. **Table 41** outlines that patients and caregivers had been hospitalised on average for a similar number of nights (11.8 and 11.2 nights) at baseline. For patients, this number was much lower at

follow-up, whereas caregivers' average hospitalisation increased from 11.2 to 13.7 nights. In comparison, the diary data in the same table show that patients had a similar number of hospital nights. Caregivers, on the other hand, not only were different but instead of showing an increase of number of nights in hospital the table shows a decrease by almost 50% compared to baseline. A closer look into the data revealed that one of the three caregivers utilising hospital nights had not sent in the diary. This explains the difference in outcomes since this participant had stayed 28 nights in hospital. The results would be exactly the same for both tools if these 28 nights were added to the diary data.

Table 41: Hospitalisation of patients and caregivers at baseline and follow-up (questionnaire and diary data)

		Patient			Caregiver		
Time		Baseline	Follow-up		Baseline	Follow-up	
Method		Questionnaire (n = 53)	Questionnaire (n = 33)	Diary (n = 20)	Questionnaire (n = 53)	Questionnaire (n = 33)	Diary (n = 20)
Participants hospitalised	n	11	5	2	5	3	2
	%	20.8	15.2	10.0	9.4	9.1	10.0
Average number of nights per utilising participant	M	11.8	2.2	2.5	11.2	13.7	6.5

Note. Data are based on utilisation within 3 months prior to baseline- and follow-up assessment.

Caregivers of patients who had been hospitalised showed a significantly lower burden score at a $p = .05$ level ($F_{1,55} = 4.05$, $p = .049$) than those caregivers whose relatives or friends with dementia had not been hospitalised during the months prior to baseline and follow-up assessment (two-way ANOVA). One-way ANOVA showed that at follow-up patients who had been hospitalised within the 3 months prior to assessment were more progressed in their dementia (CDR: $F_{1,30} = 5.85$, $p = .022$), rated their QoL lower (QOL-ADp: $F_{1,29} = 5.64$, $p = .024$) and had a worse health status (Comorbidities p: $F_{1,27} = 10.15$, $p = .004$; Comorbidities proxy: $F_{1,30} = 4.98$, $p = .033$). All these one-way ANOVA follow-up findings were confirmed using correlation analysis.

Two-way ANOVA indicated that caregivers who had been hospitalised within the 3 months prior to baseline or follow-up felt less supported by family or friends (MSPSS: $F_{1,55} = 6.78$, $p = .012$) than caregivers who had no hospital stay. A similar result was found using one-way ANOVA where the MSPSS score was lower for utilising caregivers ($F_{1,30} = 4.26$, $p = .048$) as compared to non-utilising caregivers and confirmed with a significant correlation ($r = .353$, $p = .048$).

Table 42 shows that according to the questionnaire the majority of participants saw their general practitioners (GPs) at baseline and follow-up. More caregivers than PWDs saw their GPs and the percentage of participants visiting their GPs were lower for both groups at the time of the second assessment. An additional one-third of PWDs and about one-tenth of caregivers not only visited their GPs but also a specialist doctor (such as psychiatrist, surgeon, ophthalmologist, radiologist, cardiologist and oncologist). At baseline, only 5.7% of PWDs had not seen any doctor during the 3 months prior to the assessment. This percentage increased until follow-up to 12.1% with the number of average visits per utilising patient dropping from 3.1 visits at baseline to 2.5 visits 1 year later. Even though the percentage of caregivers not visiting any doctor like PWDs also increased at follow-up (24.2%) the average number of visits did not decrease but increased from 1.8 to 2.3.

Table 42: GP and medical specialist visits of patients and caregivers at baseline and follow-up (questionnaire and diary data)

		Patient			Caregiver		
Time		Baseline	Follow-up		Baseline	Follow-up	
Method		Questionnaire (n = 53)	Questionnaire (n = 33)	Diary (n = 20)	Questionnaire (n = 53)	Questionnaire (n = 33)	Diary (n = 20)
Participants who saw only a GP	<i>n</i>	33	17	9	36	21	10
	%	62.3	51.5	45.0	67.9	63.6	50.0
Participants who saw only a specialist	<i>n</i>	0	1	0	1	0	0
	%	0.0	3.0	0.0	1.9	0.0	0.0
Participants who saw a GP and a specialist	<i>n</i>	17	11	7	5	4	4
	%	32.1	33.3	35.0	9.4	12.1	20.0
Participants who saw neither a GP nor a specialist	<i>n</i>	3	4	4	11	8	6
	%	5.7	12.1	20.0	20.8	24.2	30.0
Average number of visits per utilising participant	<i>M</i>	3.1	2.5	not assessed	1.8	2.3	not assessed

Key. GP, general practitioner.

Note. Data are based on utilisation within 3 months prior to baseline- and follow-up assessment.

Table 43 shows patients' out-of-home care utilisation across 1 year from baseline until follow-up assessment based on the diaries. The average number of hospital nights per utilising patient peaked during the third quartile. GP, specialist and nurse visits are presented further in Figure 36 and Figure 37.

Table 43: Patient utilisation of professional out-of-home care from baseline to follow-up (diary data)

	Months 1-3 (n = 42)			Months 4-6 (n = 34)			Months 7-9 (n = 26)			Months 10-12 (n = 20)		
	Patients utilising		Average utilisation	Patients utilising		Average utilisation	Patients utilising		Average utilisation	Patients utilising		Average utilisation
	n	%	M	n	%	M	n	%	M	n	%	M
Overnight hospitalisation	6	14.3	6.3 (nights)	3	8.8	5.1 (nights)	1	3.8	14.0 (nights)	2	10.0	2.5 (nights)
GP	30	71.4	58	24	70.6	76	18	69.2	42	16	80.0	34
Psycho-geriatrician	20	47.6	70	7	20.6	76	4	15.4	45	3	15.0	23
Specialist	21	50.0	89	14	41.2	140	6	23.1	53	6	30.0	54
Nurse	16	38.1	41	6	17.6	69	8	30.8	36	6	30.0	54

Key. GP, general practitioner.

Note. Average utilisation is indicated in minutes unless stated otherwise.

Figure 36 shows that the average length of patients' doctor and nurse contacts peaked for all four types of professionals during the second quartile. Overall, specialist visits took on average the longest with up to 140 minutes per visit, followed by contacts with a psycho-geriatrician and GP. Nurse contacts were the quickest during the first 9 months of study participation. But interestingly, nurse visits were also the only type of professional out-of-home-care visit which increased towards the end of the year.

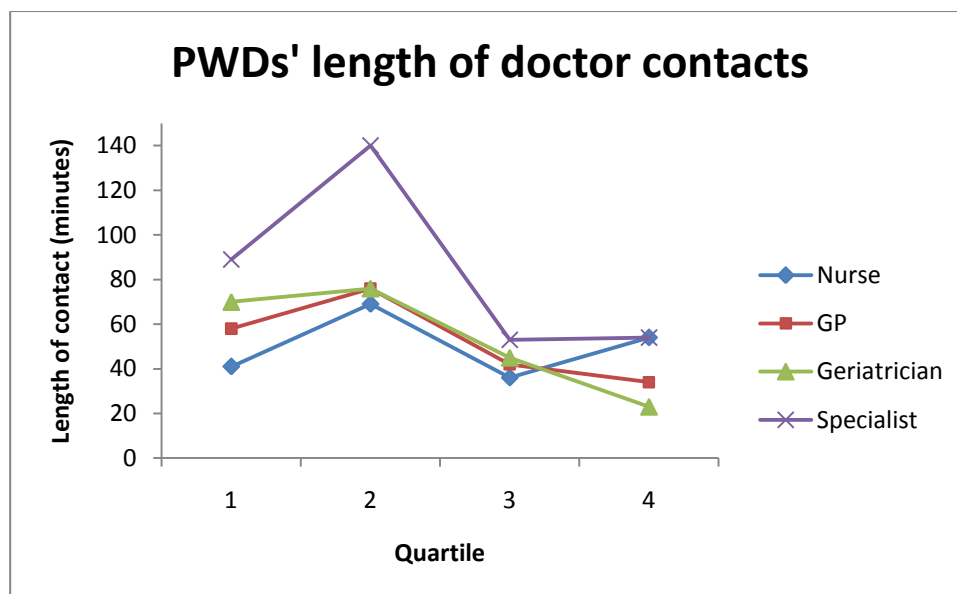


Figure 36: Average length of patients' doctor visits from baseline to follow-up (diary data)
 Key. GP, general practitioner. PWDs', persons' with dementia; Geriatrician, psycho-geriatrician.

However, **Figure 37** shows that GPs (not specialists) were seen by the highest percentage of patients with around 70% across the first 9 months and increasing to even 80% during the last quartile. Psycho-geriatricians were seen by almost half of all patients within 3 months after baseline which was likely related to the routine follow-up visit at TPMH within 3 months of the initial diagnosis. In the following months these visits dropped to 15% at follow-up.

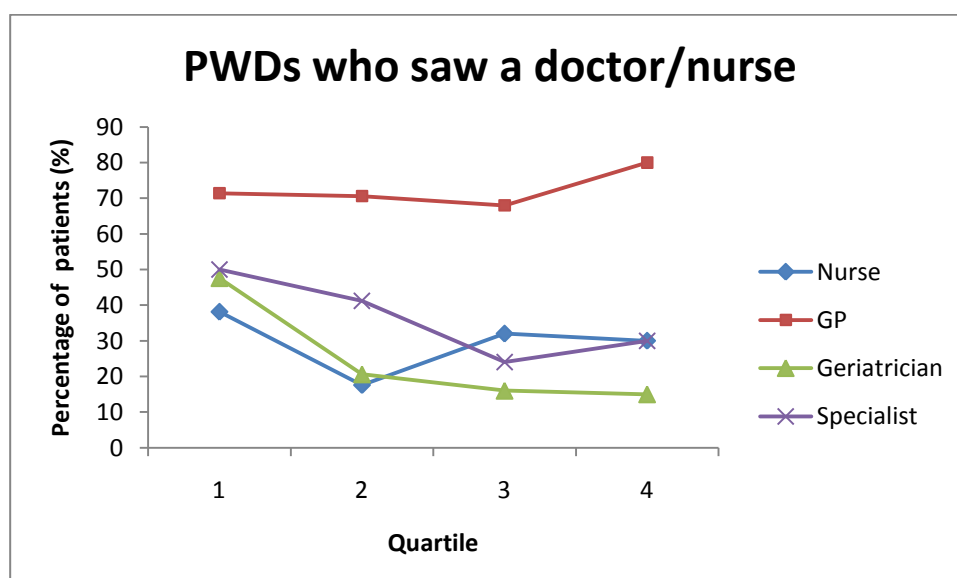


Figure 37: Percentage of patients visiting doctors from baseline to follow-up (diary data)
 Key. GP, general practitioner. PWDs, persons with dementia; Geriatrician, psycho-geriatrician.

Two-way ANOVA resulted in no significant differences between patient groups regarding their doctor/nurse utilisation prior to baseline and follow-up assessment. However, using one-way

ANOVA it was revealed that at follow-up caregivers of PWDs who saw a medical professional during the 3 months prior to follow-up rated their QoL significantly lower (QOL-ADc: $F_{1,30} = 4.15$, $p = .050$), they were more distressed (NPI-D: $F_{1,30} = 4.89$, $p = .035$) and depressed (GDS: $F_{1,30} = 5.22$, $p = .030$). Using Pearson's correlation, no significant link was found between patients' doctor utilisation and their QoL ratings. However, it was confirmed that caregivers of patients who saw a medical professional within the 3 months prior to follow-up were more distressed ($r = -.374$, $p = .035$) and more likely to be depressed ($r = -.385$, $p = .030$).

Table 44 presents the diary data for caregivers' out-of-home care utilisation across 1 year from baseline until follow-up. Similar to patients, the average number of hospital nights per utilising patient peaked during the third quartile. GP, specialist and nurse visits are presented further in **Figure 38** and **Figure 39**.

Table 44: Caregiver utilisation of professional out-of-home-care from baseline to follow-up (diary data)

	Months 1-3 ($n = 42$)			Months 4-6 ($n = 34$)			Months 7-9 ($n = 26$)			Months 10-12 ($n = 20$)		
	Caregivers utilising		Average utilisation	Caregivers utilising		Average utilisation	Caregivers utilising		Average utilisation	Caregivers utilising		Average utilisation
	n	%	M	n	%	M	n	%	M	n	%	M
Overnight hospitalisation	4	9.5	3.8 (nights)	2	5.9	3.5 (nights)	3	11.5	9.3 (nights)	2	10.0	6.5 (nights)
GP	27	64.3	97	19	55.9	35	15	57.7	44	14	70.0	38
Specialist	7	16.7	131	4	11.8	94	3	11.5	82	5	25.0	142
Nurse	10	23.8	29	6	17.6	43	3	11.5	50	3	15.0	45

Key. GP, general practitioner.

Note. Average utilisation is indicated in minutes unless stated otherwise. GP, general practitioner.

The average length of GP and specialist doctor visits was relatively long compared to other formal care interventions for both at baseline with 97 and 131 minutes respectively, as can be seen in **Figure 38**. Both numbers dropped significantly within the first 3 months, but specialist visits increased again to an average of 142 minutes per contact towards the end of the year up to 142

minutes whereas GP visits remained on average shorter with around 40 minutes per visits. Interestingly, nurse visits took on average as long as GP visits during most of the remaining year.

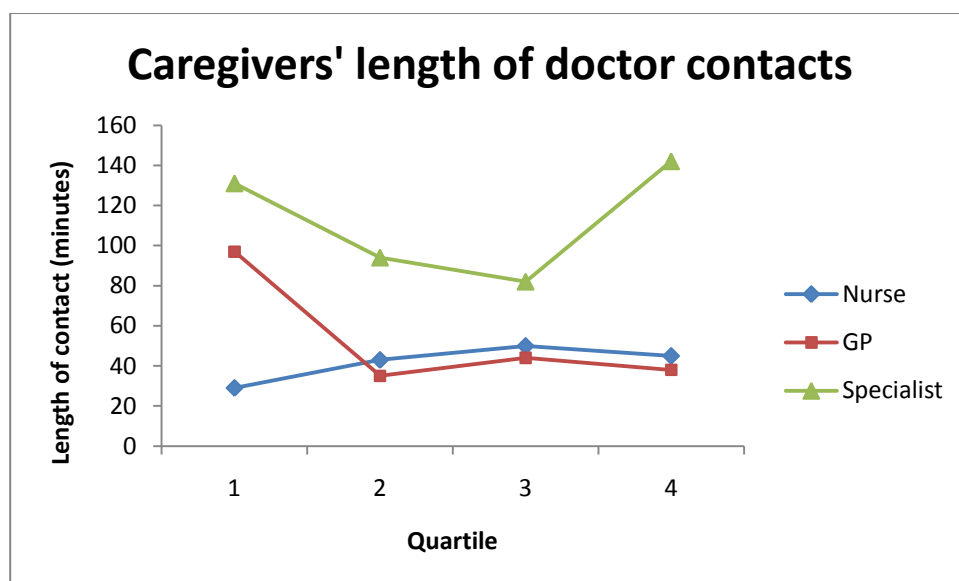


Figure 38: Average length of caregivers' doctor visits from baseline to follow-up (diary data)
Key. GP, general practitioner.

Figure 39 shows that similar to PWDs, GPs were seen by the highest percentage of caregivers compared to other medical professionals. Up to five times as many caregivers saw a GP as compared to a specialist or a nurse. Percentages increased for all three types of medical professionals towards the end of the year indicating a higher resource utilisation in caregivers with progressing dementia.

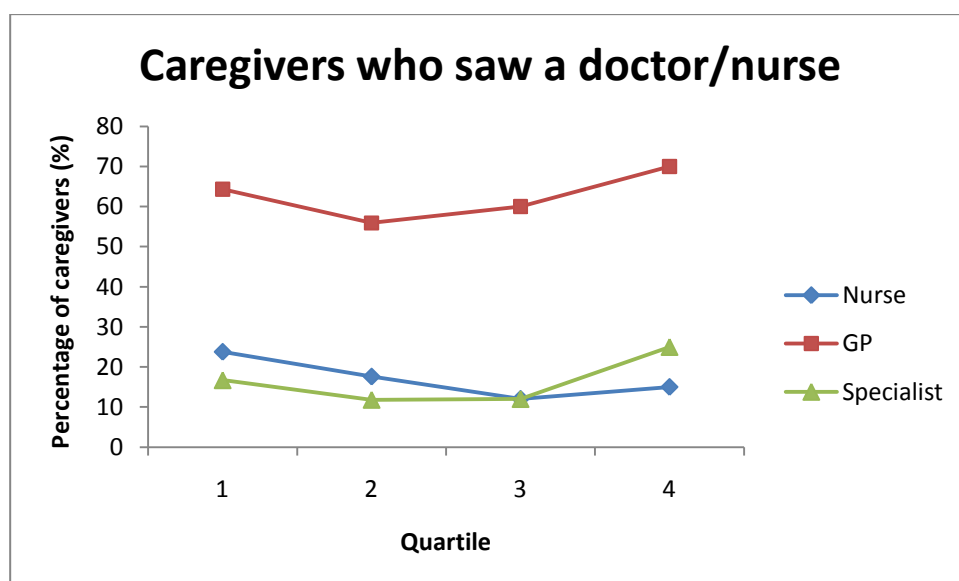


Figure 39: Percentage of caregivers visiting doctors from baseline to follow-up (diary data)
Key. GP, general practitioner.

Two-way ANOVA resulted in no significant differences between caregiver groups who had seen a medical professional and those who had not prior to baseline and follow-up assessment regarding their QoL outcomes. However, using one-way ANOVA it was observed that at follow-up caregivers who saw a medical professional during the 3 months prior to follow-up looked after PWDs who had a significantly higher BADLS scores ($F_{1,30} = 4.47, p = .043$) which was confirmed with a significant correlation ($r = -.359, p = .043$). It might be that caregivers of PWDs with a greater functional impairment require more support from their GPs and other medical professional to help them cope.

5.7.2.3 Professional in-home care

The following four support options for PWDs were measured as in-home care: visiting nurse, personal care assistance, domestic assistance and meals-on-wheels. All services were measured at baseline and follow-up using the service utilisation questionnaire. Each service was quantified in terms of its utilisation, number of care contacts within 2 weeks prior to the assessments and average length of each contact. As pointed out earlier (p. 179), the researcher found that in this study the QoL of PWDs not simply decreased with decreasing cognition but with the overall illness progression. However, the degree of cognitive impairment was an important predictor for the level of formal care needed. At baseline the severity of cognitive impairment (3MS) was negatively correlated with the number of in-home care contacts received within the 2 weeks prior to assessment ($r = -.353, p = .011$), which means that PWDs with decreased cognition received more in-home care than PWDs with less cognitive impairment. At follow-up, the same relationship still approached statistical significance ($r = -.333, p = .062$) and the average time spent on these formal care contacts was now also strongly correlated with patients' level of cognitive impairment ($r = -.421, p = .016$). **Table 45** outlines the descriptive outcomes for all four in-home care options.

Table 45: Patient formal in-home care utilisation at baseline and follow-up (questionnaire data)

		Baseline (<i>n</i> = 52)	Follow-up (<i>n</i> = 32)
Visiting nurse			
Patients who received assistance	<i>n</i>	10	4
	%	19.2	12.5
Average number of visits per utilising patient	<i>M</i>	10.9	15.0
Average length of visits per utilising patient	<i>M (minutes)</i>	15.8	16.3
Personal care assistance			
Patients who received assistance	<i>n</i>	9	3
	%	17.3	9.4
Average number of contacts per utilising patient	<i>M</i>	6.0	5.3
Average length of contacts per utilising patient	<i>M (minutes)</i>	43.3	45.0
Domestic assistance			
Patients who received assistance	<i>n</i>	22	13
	%	42.3	40.6
Average number of contacts per utilising patient	<i>M</i>	1.9	2.1
Average length of contacts per utilising patient	<i>M (minutes)</i>	77	97
"Meals-on-wheels"			
Patients who received meals	<i>n</i>	5	3
	%	9.6	9.4
Average number of deliveries per utilising patient	<i>M</i>	6.0	7.0

Note. Data are based on utilisation within 2 weeks prior to baseline- and follow-up assessment.

Surprisingly, the percentage of patients utilising in-home care services decreased for all four services within the year between baseline and follow-up assessment (**Figure 40**).

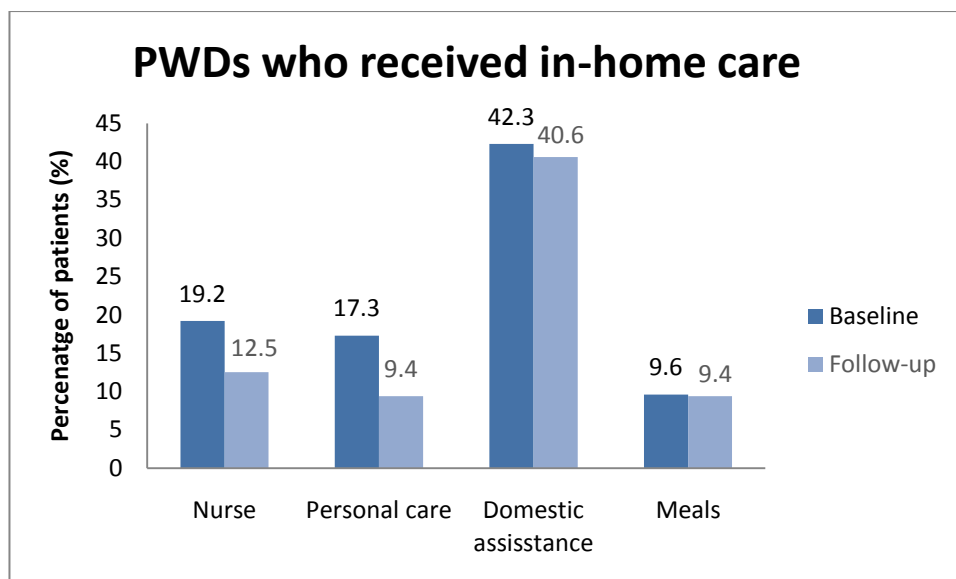


Figure 40: Percentage of patients who received in-home-care at baseline and follow-up (questionnaire data)

Key. PWDs, persons with dementia.

Note. Data are based on utilisation within 2 weeks prior to baseline- and follow-up assessment.

However, at the same time the average number of contacts and meals-on-wheels deliveries increased for all services with the exception of personal care assistance (**Figure 41**).

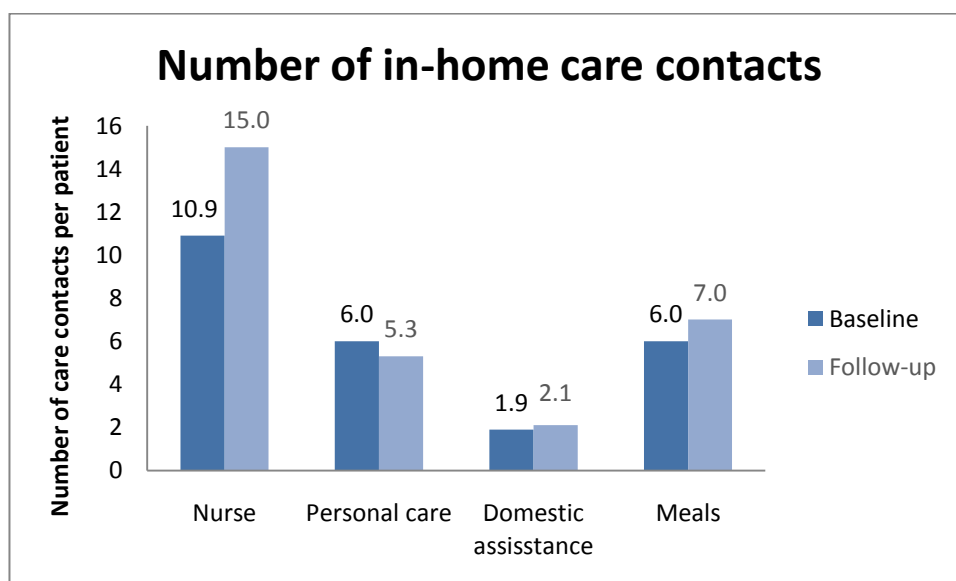


Figure 41: Average number of in-home care utilisations per patient at baseline and follow-up (questionnaire data)

Note. Data are based on utilisation within 2 weeks prior to baseline- and follow-up assessment.

Additionally, the average length of all in-home care services also increased from baseline to follow-up (**Figure 42**).

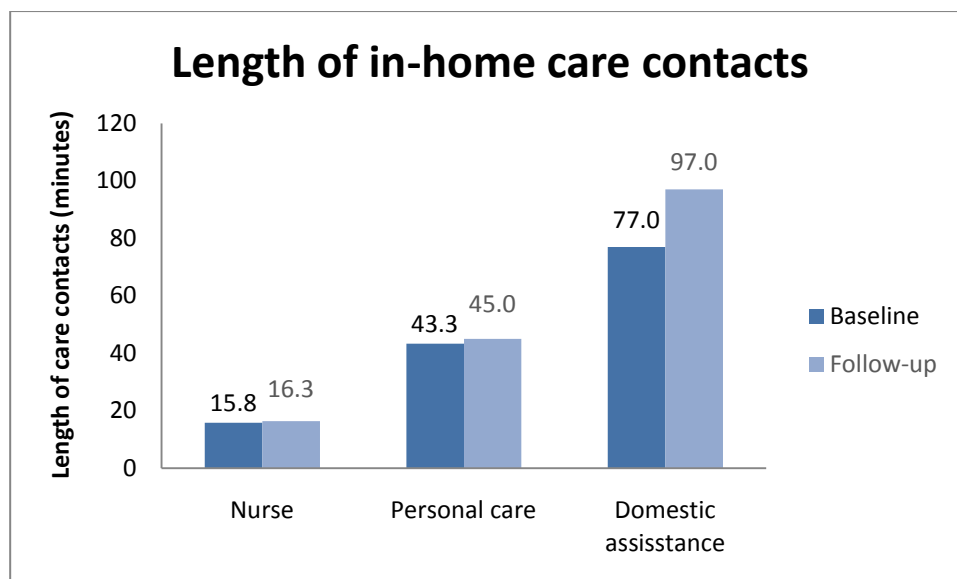


Figure 42: Average length of in-home care contacts per utilising patient at baseline and follow-up (questionnaire data)
 Note. Data are based on utilisation within 2 weeks prior to baseline- and follow-up assessment.

The data in **Table 46** were obtained from Nurse Maude, the biggest service provider for in-home care in Canterbury as control data since these items were not collected using the diaries. All three services, visiting nurse, personal care and domestic assistance, show higher percentages of patients utilising them compared to the questionnaire data in the table above. Partly this could be explained by the much smaller number of participants who were Nurse Maude clients ($n = 22$) compared to the number of study participants to whom the questionnaire had been administered ($n = 52$). Similar to the questionnaire data, the average number and length of nurse home-visits per utilising patients increased within the year. Different though, personal and domestic assistance both decreased in number and length of visits. Again, it seems important to consider that these outcomes were based on only 9 clients at follow-up. Also, a direct comparison is difficult, since Nurse Maude provided cumulative data for the entire year after the baseline assessment as well as for the year after the follow-up assessment. Results presented in **Table 46** are based on calculations for an average utilisation within 2 weeks of each year. Regardless, a similar analysis for all clients of Nurse Maude would certainly provide very useful information.

Table 46: Patient formal in-home care utilisation at baseline and follow-up (Nurse Maude data)

		Year after baseline (<i>n</i> = 22)	Year after follow-up (<i>n</i> = 9)
Visiting nurse			
Patients who received assistance	<i>n</i>	9	3
	%	40.9	33.3
Average number of visits per utilising patient	<i>M</i>	3.5	13.3
Average length of visits per utilising patient	<i>M (minutes)</i>	93	324
Personal care assistance			
Patients who received assistance	<i>n</i>	5	1
	%	22.7	11.1
Average number of contacts per utilising patient	<i>M</i>	3.8	1.8
Average length of contacts per utilising patient	<i>M (minutes)</i>	170	83
Domestic care assistance			
Patients who received assistance	<i>n</i>	4	4
	%	18.2	44.4
Average number of contacts per utilising patient	<i>M</i>	2.1	0.9
Average length of contacts per utilising patient	<i>M (minutes)</i>	181	82

Note. Data are based on utilisation within the year between baseline- and follow-up assessments and within the year after follow-up assessment. Data were then used to calculate the average utilisation within 2 weeks of both years.

One-way ANOVA analysis showed that the length of formal care visits increased between baseline and follow-up assessments approaching statistical significance ($F_{1,62} = 3.84, p = .055$). This indicates that formal care might become increasingly important to sustain QoL in PWDs and their caregivers over time (included in-home care and time spent in day care and sitter service). This theory was supported by follow-up Pearson's correlations. There was a clear trend that more distressed caregivers looked after PWDs who were less likely to receive personal care assistance ($r = .338, p = .059$), and if they received such support it was during fewer ($r = -.336, p = .060$) and shorter contacts ($r = -.320, p = .074$). In other words, caregivers were more distressed if patients received less in-home support with their personal care needs. An alternative explanation for these findings

is that caregivers who were most distressed had less energy to identify and coordinate these support services.

Two-way ANOVA was performed to detect differences between patients who utilised a certain in-home care service and those who did not during the 3 months prior to baseline and follow-up assessment. The only significant difference was found for patients who had a nurse supporting them in their home during the 3 months prior to baseline and follow-up assessment. **Table 47** shows that the patients who utilised a visiting nurse rated their QoL considerably higher at follow-up compared to those who did not receive nurse assistance and who rated their QoL only marginally higher ($F_{1,55} = 4.18, p = .046$). No significant differences were found at follow-up using one-way ANOVA and Pearson's correlation.

Table 47: Two-way ANOVA: difference between PWDs utilising 'visiting nurse' assistance and those who did not utilise this service at baseline and at follow-up regarding their QOL-ADp ratings (questionnaire data)

	PWDs utilising (mean \pm SE)	PWDs non-utilising (mean \pm SE)	$F_{1,55}$	p
Visiting nurse	$n = 10$	$n = 42$		
QOL-ADp baseline	35.33 ± 2.94	39.29 ± 0.96		
	$n = 4$	$n = 28$	4.18	.046
QOL-ADp follow-up	45.33 ± 2.94	40.32 ± 1.02		

Key. PWDs, persons with dementia; QOL-ADp, Quality of Life-Alzheimer Disease Scale patient rating.

* $p \leq .050$

Further one-way ANOVA analyses showed that there were statistically significant (and some approaching significance) differences between patients who received personal care and domestic care assistance during the 3 months prior to follow-up assessment and those patients who did not receive such service (see **Table 48**)

Table 48: One-way ANOVA: differences between PWDs utilising personal or/and domestic care assistance and those who did not utilise these services at follow-up regarding their QoL outcomes (questionnaire data)

	PWDs utilising (mean ± SE)	PWDs non-utilising (mean ± SE)	$F_{1,30}$	p
Personal care	$n = 3$	$n = 29$		
CDR	2.33 ± 0.33	1.09 ± 0.10	14.58	.001
QOL-ADp	34.33 ± 0.88	41.36 ± 0.94	5.81 ¹	.022
BADLS	26.67 ± 9.39	10.24 ± 1.14	13.86	.001
NPI-D	0.33 ± 0.33	8.86 ± 1.38	3.86	.059
GDS	8.67 ± 1.20	11.14 ± 0.40	3.51	.071
Domestic care	$n = 13$	$n = 19$		
CDR	1.50 ± 0.23	1.00 ± 0.09	5.26	.029
BADLS	15.38 ± 3.08	9.32 ± 1.27	4.19	.050
GDS	10.08 ± 0.66	11.47 ± 0.47	3.15	.086

Key. PWDs, persons with dementia; QoL, quality of life; CDR, Clinical Dementia Rating Scale; QOL-ADp, Quality of Life-Alzheimer Disease Scale patient rating; BADLS, Bristol Activities of Daily Living Scale; NPI-D, Neuropsychiatric Inventory-Distress Scale; GDS, Geriatric Depression Scale.

¹ $F_{1,29}$

Those PWDs who had received assistance with their personal care within the 3 months prior to follow-up were at the second assessment significantly further progressed in their dementia, rated their QoL lower and were more impaired in their level of daily functioning. There was a trend, however, that caregivers of these PWDs were less distressed and depressed than caregivers of patients who had not received personal care assistance (see **Table 48**). The statistically significant findings were confirmed using correlation analysis. Additionally, there was also a significant negative correlation between personal care utilisation and the type of dementia at follow-up ($r = -.385$, $p = .030$), which means that patients with VD or mixed dementia were more likely to receive personal care than participants with AD.

The data in the table above also indicate that PWDs who required assistance with domestic tasks were further advanced in their illness and more functionally impaired which was also found using correlation analysis ($r = -.386$, $p = .029$; $r = -.350$, $p = .050$ respectively). Again, interestingly, there was a trend that caregivers of these patients were less depressed than caregivers of PWDs who had no domestic assistance.

5.7.2.4 Summary of findings related to medical and domestic supports/interventions

In summary, the hypothesis, which stated that the utilisation of medical interventions would improve PWDs' and caregivers' QoL over time, was not supported for most types of medical interventions investigated here. However, caregivers did feel less burdened if the PWD had been hospitalised during the year, which would support the hypothesis. On the other hand, caregivers also felt less supported if they themselves had been hospitalised. It was also found that patients who had a nurse supporting them in their homes had significantly higher QoL ratings compared to those who did not utilise this service and whose QoL remained the same over the 12-months period. There were also strong indications that caregivers were more distressed if patients received less in-home support with their personal care and domestic needs. However, causality is not easily determined here and therefore it is also possible that caregivers who were most distressed had less energy to identify and coordinate these support services.

The hypothesis that taking advantage of available support options resulted in fewer negative changes regarding patients' QoL was supported by the data. For example, it was shown that patients using ChEIs or Memantine increased less in their neuropsychiatric and behavioural symptoms than other patients (p. 235).

In order to answer the question - if higher levels of caregiver stress are associated with an increase in the use of medical services - Pearson's correlation analysis was performed. The results show that caregivers' distress levels (NPI-D) were significantly associated with the following outcomes at baseline:

- PWDs' hospitalisation ($r = -.359, p = .009$),
- caregivers' utilisation of mental health medication ($r = -.286, p = .040$).

These results indicate that caregivers felt more distressed if their relatives had been hospitalised prior to baseline interview. Those caregivers were more likely to use some mental health medication such as an anti-depressant. Otherwise, no significant correlations between carer

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distress and medical service utilisation were observed. These findings would support the hypothesis. At follow-up, there were significant correlations between caregivers' distress scores and the following outcomes:

- PWDs' utilisation of doctor contacts ($r = -.374, p = .035$),
- PWDs' number of doctor contacts ($r = .368, p = .039$),
- PWDs' utilisation of mental health medication ($r = -.438, p = .012$),
- caregivers' utilisation of mental health medication ($r = -.377, p = .034$).

It can be concluded from these findings that caregivers felt more distressed if the PWD saw a medical professional and if the PWD saw a medical professional more often than other PWDs who had fewer doctor contacts. Caregivers with higher distress levels were also more likely to take some mental health medication and to look after patients who took such medication. Again, **these findings support the hypothesis that higher levels of caregiver stress can cause an increase in the use of medical services**. However, considering also that no significant out-of-pocket expenses occurred for caregivers' mental health medication the hypothesis is still supported but with few implications for the overall costs.

Even though the data from this study supported the hypothesis that higher levels of caregiver stress are associated with an increase in the use of medical services (such as patients' doctor contacts and hospitalisation), it seems more likely that distress was a result rather than a cause. This theory is supported by the finding that, at follow-up, there was also a clear trend that more distressed caregivers looked after PWDs who were less likely to receive personal care assistance ($r = .338, p = .059$), and if they received such support it was during fewer ($r = -.336, p = .060$) and shorter contacts ($r = -.320, p = .074$). In other words, caregivers were more distressed if patients received less in-home support. Again, distress seems to be the result rather than the cause, but this outcome points towards in-home support as an important intervention not only regarding

patients' QoL but also caregivers' QoL outcomes. This agrees with the findings presented in Table 47 (p. 250) and Table 48 (p. 251).

5.7.3 Educational supports/interventions

The following results relate to the hypotheses as listed under point 2.c of chapter 3.3 (p. 114): educational interventions can improve caregiver outcomes such as depression, burden and reactivity to difficult behaviours. Such intervention can also positively impact on PWDs' neuropsychiatric and behavioural symptoms and QoL (proxy rated).

Alzheimers Canterbury offered two different seminars during the time of data collection: firstly, monthly meetings to educate caregivers about the disease process; secondly, training to improve caregivers' coping skills or problem solving ('Making-a-Difference' course) which consisted of 10 training-units. For the purpose of this analysis, both seminars were summed into one intervention which was measured in minutes of participation using the diaries. **Figure 43** shows that only 9.5% of caregivers attended a seminar at the beginning of the 12 months, with numbers dropping constantly during the following months. During the last quartile none of the caregivers who had sent in the diaries was attending either of the seminars anymore. It seems that the interest in these seminars and the need for information are particularly high during the first few months after the PWD has been diagnosed.

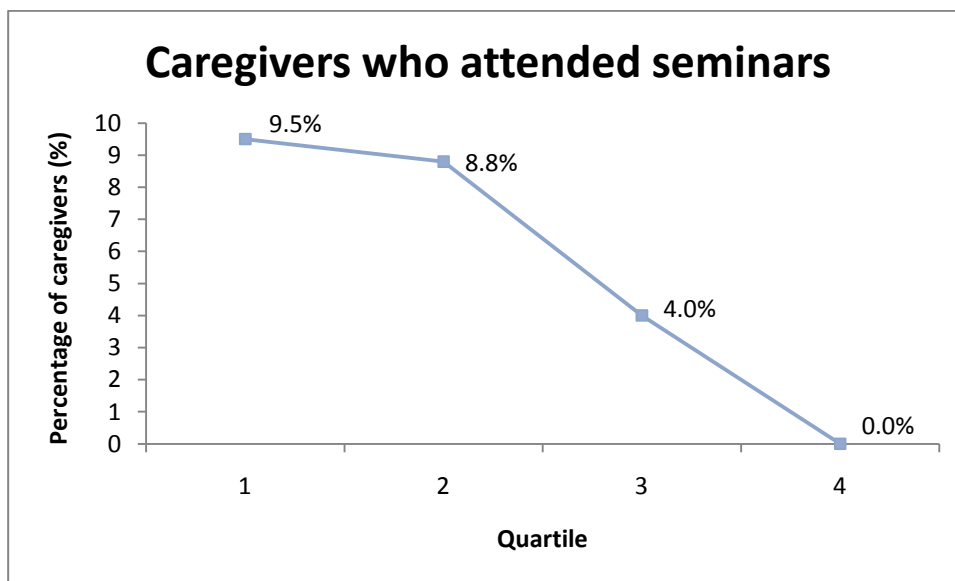


Figure 43: Percentage of caregivers attending educational seminars from baseline to follow-up (diary data)

However, not only the number of caregivers attending these seminars dropped but also the average length of time per meeting dropped by half every quartile as can be seen in **Figure 44**.

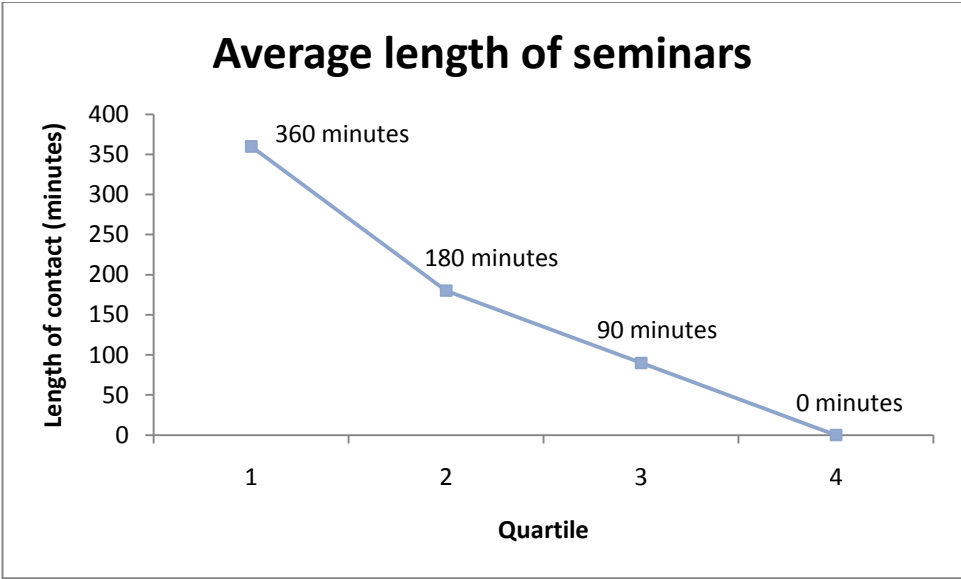


Figure 44: Average length of educational seminars for caregivers from baseline to follow-up (diary data)

The explanation for these numbers might be the fact that the ‘Making-a-Difference’ courses are on average 180 minutes weekly whereas other seminars are often only 90 minutes monthly. Numbers therefore would vary depending if participants attended the ‘Making-a-Difference’ courses or the monthly seminars or both.

Diary data of 19 caregivers could be analysed across the entire year. Eight of these caregivers had participated at some point during the year in an educational seminar offered by Alzheimers Canterbury (42.1%). Using one-way ANOVA, no statistically significant differences were observed between the group of caregivers who attended a seminar during the year and the group of those who did not attend such a meeting. However, there was a trend that attendees looked after patients who were on average less depressed and had fewer neuropsychiatric and behavioural symptoms and whose QoL was rated higher than non-attendees (**Table 49**). Caregivers who went to these seminars also rated their own QoL higher and they felt more supported by family and friends than other caregivers (**Table 49**). The same trends were observed using Pearson’s correlation analysis.

Table 49: One-way ANOVA: differences between caregivers utilising seminars and those who did not utilise this intervention during 12 months regarding their QoL outcomes (diary data)

	Caregivers utilising (mean \pm SE)	Caregivers non-utilising (mean \pm SE)	$F_{1,17}$	p
Educational seminars	$n = 8$	$n = 11$		
QOL-ADproxy	38.50 ± 1.05	35.73 ± 1.37	2.26	.151
CSDD	3.88 ± 1.33	6.73 ± 0.93	3.32	.086
NPI	8.38 ± 1.25	16.64 ± 4.22	2.63	.123
QOL-ADc	42.13 ± 1.36	39.82 ± 0.55	3.07	.098
MSPSS	73.00 ± 2.83	65.82 ± 2.99	1.80	.111

Key. QoL, quality of life; QOL-ADproxy, Quality of Life-Alzheimer Disease Scale proxy rating; CSDD, Cornell Scale for Depression in Dementia; NPI, Neuropsychiatric Inventory; QOL-ADc, Quality of Life-Alzheimer Disease Scale caregiver rating; MSPSS, Multidimensional Scale of Perceived Social Support.

In summary, **it was not found that the seminars offered by Alzheimers Canterbury improved caregivers' depression, burden or reactivity to difficult behaviours** and the respective hypothesis stated at the beginning of this section was therefore not supported. **However, a trend was shown that this type of intervention might positively impact on PWDs' neuropsychiatric and behavioural symptoms and QoL (proxy rated).** So even if the hypothesis was not clearly supported the results were still in its favour.

The hypothesis that the utilisation of educational supports and interventions would improve PWDs' and caregivers' QoL over time could not be determined since none of the 19 caregivers who had provided data in the diaries was still utilising seminar at the end of the year.

5.7.4 Social supports/interventions

Social support or interventions were defined as those which concerned the process of developing a support system for the PWDs and their caregiver. This section, however, is only concerned with formal social support options which included day care, sitter service and support groups for PWDs ('Memory Groups') and for caregivers ('Carers' Group'). Data on informal support, which caregivers received from family and friends, were obtained at baseline and follow-up, using the MSPSS. The results of this questionnaire were described earlier in the section 'Informal social support' (p. 208).

5.7.4.1 Day care and sitter service

Table 50 summarises how day care and sitter services were utilised by PWDs. It can be seen that the percentage of patients attending day care doubled within the year with the average number of visits per person increasing from 1.0 to 1.65 per week. It is common for day care clients to start attending day care once a week and later to increase to 2 days per week depending on individual needs. This seems to be reflected in these numbers. The average time of about five and a half hours per day care visit remained about the same over the year which was to be expected.

Table 50: Patients' day care and sitter service utilisation at baseline and follow-up (questionnaire data)

Baseline (<i>n</i> = 52)		Follow-up (<i>n</i> = 32)
Day care		
Patients who attended day care	<i>n</i>	5
	%	9.6
Average number of visits per utilising patient	<i>M</i>	2.0
Average length of visits per utilising patient	<i>M (minutes)</i>	336
Sitter service		
Patients who received sitter service	<i>n</i>	1
	%	1.9
Average number of contacts per utilising patient	<i>M</i>	2.0
Average length of contacts per utilising patient	<i>M (minutes)</i>	240

Note. Data are based on utilisation within 2 weeks prior to baseline- and follow-up assessment.

Table 51 outlines the results of a one-way ANOVA analysis regarding differences in day care utilisation between baseline and follow-up assessment. As opposed to the above table this analysis was based on matched pairs from the entire sample, not just the ones utilising this intervention. Even then, the results of the descriptive analysis were confirmed with statistically significant differences between baseline and follow-up in number of patients utilising this intervention, the average number of visits within 2 weeks and the average length of each visit at $p \leq .05$ levels.

Table 51: One-way ANOVA: differences in day care utilisation between baseline and follow-up (matched pair questionnaire data)

		Baseline (Mean ± SE) (n = 32)	Follow-up (Mean ± SE) (n = 32)	$F_{1,62}$	p
Day care					
Patients who attended day care	1: utilised	1.97 ± 0.31	1.81 ± 0.70	4.14	.046
	2: not-utilised				
Average number of visits	<i>M</i>	0.06 ± 0.06	0.63 ± 0.26	4.40	.040
Average length of visits	<i>M (minutes)</i>	11.25 ± 11.25	64.69 ± 24.25	4.00	.050

Note. Data are based on utilisation within 2 weeks prior to baseline- and follow-up assessment.

* $P \leq .050$

Having somebody coming in and spending some time with the PWD is another form of respite care available to caregivers of PWDs in Canterbury. This service became increasingly popular over the year with six times as many caregivers utilising this support option at follow-up as compared to baseline. Sitter service is usually offered once a week which is replicated here. The average time per visit dropped from 240 minutes at baseline to 150 minutes at follow-up. However, it has to be considered that the baseline data were only calculated based on data from one person utilising this service.

Two-way ANOVA was performed to detect differences between patients who utilised a day care and/or sitter service and those who did not during the 3 months prior to baseline and follow-up assessment. No statistically significant differences were found between the two groups. There was a trend ($F_{1,55} = 2.65$, $p = .109$), however, that PWDs who attended day care had a lower CDR score at follow-up as compared to baseline. This implies that PWDs who did not utilise this intervention had on average a higher CDR score at follow-up compared to baseline indicating a more progressed stage of dementia. However, it is unlikely that PWDs who went to day care reversed their illness progression but rather that a number of these PWDs had a moderate CDR score and discontinued the study and other patients with a lower CDR score started day care within the year.

A second trend was observed for patients who received the sitter service. These patients tended to have a decreased BADLS score at follow-up, whereas those who did not utilise this service tended to increase in their BADLS score ($F_{1,55} = 3.19, p = .080$). Again, these results have to be treated with caution, since only one PWD utilised this service at baseline but six at follow-up making a comparison difficult.

A one-way ANOVA analysis confirmed that day care does not reverse the illness. It showed that there were statically significant differences between patients who attended day care during the 3 months prior to follow-up and those who did not. PWDs at day care were more advanced in their illness, more functionally impaired and their caregivers rated the QoL of these patients lower than caregivers of patients who did not utilise day care. Caregivers of PWDs using day care also showed a trend to have a lower burden score than others ($p = .088$). The results are summarised in **Table 52**.

Table 52: One-way ANOVA: differences between PWDs utilising day care or/and sitter service and those who did not utilise these services at follow-up regarding their QoL outcomes (questionnaire data)

	PWDs utilising (mean \pm SE)	PWDs non-utilising (mean \pm SE)	$F_{1,30}$	p
Day care	$n = 6$	$n = 26$		
CDR	1.67 \pm 0.33	1.10 \pm 0.11	4.20	.049
QOL-ADproxy	32.00 \pm 1.21	36.54 \pm 0.77	7.00	.013
BADLS	19.33 \pm 5.32	10.04 \pm 1.27	6.65	.015
BI	31.17 \pm 5.44	20.38 \pm 2.65	3.12	.088
Sitter service	$n = 6$	$n = 26$		
CDR	1.86 \pm 0.34	1.02 \pm 0.08	12.64	.001
QOL-ADproxy	32.57 \pm 1.49	36.56 \pm 0.76	5.88	.022
QOL-ADc	37.00 \pm 1.25	41.08 \pm 0.66	8.33	.007

Key. PWDs, persons with dementia; QoL, quality of life; CDR, Clinical Dementia Rating Scale; QOL-ADproxy, Quality of Life-Alzheimer Disease Scale proxy rating; BADLS, Bristol Activities of Daily Living Scale; BI, Zarit Burden Interview; QOL-ADc, Quality of Life-Alzheimer Disease Scale caregiver rating.

Table 52 also shows that, similar to day care, PWDs who had utilised a sitter service were significantly more progressed in their dementia than those who had used this support within the 3 months prior to follow-up (CDR, $p = .001$). Caregivers of patients with sitter service rated their own

QoL lower and rated the patients QoL lower at follow-up compared to other caregivers as a one-way ANOVA showed (**Table 52**). All statistically significant one-way ANOVA findings were confirmed using Pearson's correlation:

- stage of illness (day care: $r = -.350, p = .049$; sitter: $r = -.544, p = .001$),
- PWDs' QoL: proxy ratings (day care: $r = .435, p = .013$; sitter: $r = .405, p = .022$),
- level of daily functioning (day care: $r = -.426, p = .015$),
- caregivers' QoL (sitter: $r = .466, p = .007$).

5.7.4.2 Support group for patients – Memory Group

Table 53 gives an overview of numbers and percentages of PWDs participating in a support group during the year of study participation and of the average duration of these meetings.

Table 53: Patient utilisation of support group ('Memory Group') from baseline to follow-up (diary data)

Months 1-3 (<i>n</i> = 42)			Months 4-6 (<i>n</i> = 34)			Months 7-9 (<i>n</i> = 25)			Months 10-12 (<i>n</i> = 20)		
Participants utilising		Average length of meeting	Participants utilising		Average length of meeting	Participants utilising		Average length of meeting	Participants utilising		Average length of meeting
<i>n</i>	%	<i>M</i>	<i>n</i>	%	<i>M</i>	<i>n</i>	%	<i>M</i>	<i>n</i>	%	<i>M</i>
6	14.3	343	6	17.6	333	4	16.0	248	1	5.0	270

Note. Average utilisation is indicated in minutes unless stated otherwise.

Figure 45 shows that only a small percentage of patients attended the support group which Alzheimers Canterbury offers specifically for the PWD. Numbers were relatively stable during the first 9 months with an average of about 1 in 6 PWDs attending the support group. But during the last quartile, only one person (5.0%) was still utilising this service.

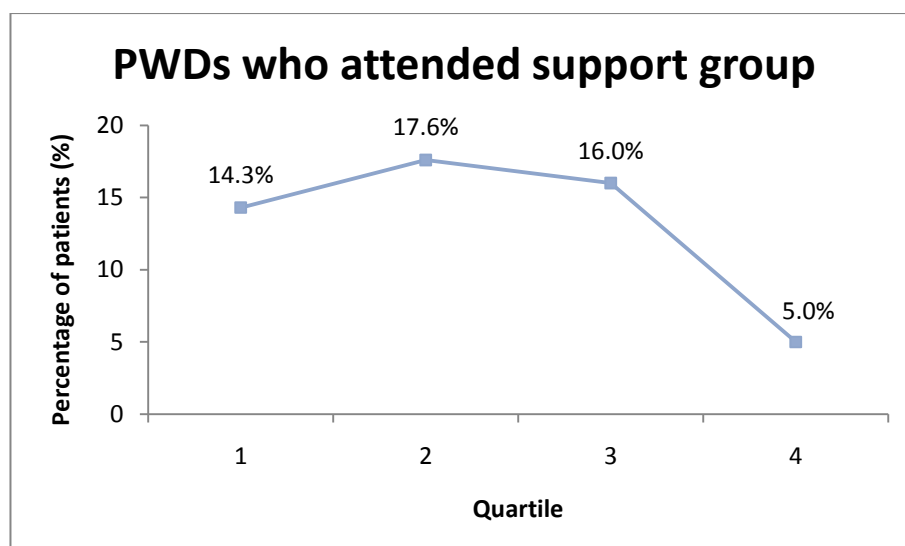


Figure 45: Percentage of PWDs attending support group from baseline to follow-up (diary data)

Key. PWDs, persons with dementia.

It could be that the progressing illness reduced participants' capabilities to continue attending the 'Memory Groups'. However, it is known to the researcher that at least one PWD was asked by the service provider to discontinue his attendance for his lack of focus on the suggested topics.

Diary data of 19 PWDs could be analysed across the entire year. The majority of these patients had participated at some point during the year in a support group (52.6%). Using one-way ANOVA no statistically significant differences were observed between the group of patients who attended a support group during the year and the group of those who did not attend such a group. However, there was a trend that attendees rated their own QoL higher and were looked after by caregivers with a higher depression score than non-attendees as can be seen from the data in **Table 54**.

Table 54: One-way ANOVA: differences between PWDs utilising support group and those who did not utilise this service during 12 months regarding their QoL outcomes (diary data)

	PWDs utilising (mean \pm SE)	PWDs non-utilising (mean \pm SE)	$F_{1,17}$	p
Memory Group	$n = 10$	$n = 9$		
QOL-ADp	42.13 \pm 1.46	39.50 \pm 1.07	2.21 ¹	.156
GDS	11.89 \pm 0.75	10.20 \pm 0.70	2.72	.118

Key. PWDs, persons with dementia; QoL, quality of life; QOL-ADp, Quality of Life-Alzheimer Disease Scale patient rating; GDS, Geriatric Depression Scale.

¹ $F_{1,16}$

Patients' QoL ratings (QOL-ADp) and caregivers depression scores (GDS) also approached statistical significance using Pearson's correlation with $p = .156$ ($r = -.349$) and $p = .118$ ($r = -.371$) respectively.

5.7.4.3 Support group for family-caregivers – Carers' Group

Table 55 gives an overview of numbers and percentages of caregivers participating in a support group during the year of study participation and of the average duration of these meetings.

Table 55: Caregiver utilisation of support group from baseline to follow-up (diary data)

Months 1-3 (<i>n</i> = 42)			Months 4-6 (<i>n</i> = 34)			Months 7-9 (<i>n</i> = 25)			Months 10-12 (<i>n</i> = 20)		
Participants utilising		Average length of meeting	Participants utilising		Average length of meeting	Participants utilising		Average length of meeting	Participants utilising		Average length of meeting
<i>n</i>	%	<i>M</i>	<i>n</i>	%	<i>M</i>	<i>n</i>	%	<i>M</i>	<i>n</i>	%	<i>M</i>
11	26.2	329	8	23.5	225	5	20.0	198	3	15.0	100

Note. Average utilisation is indicated in minutes unless stated otherwise.

At the beginning of the 12 months data collection period about 1 in 4 caregivers (26.2%) participated in the support group offered by Alzheimers Canterbury as can be seen from the data in **Figure 46**.

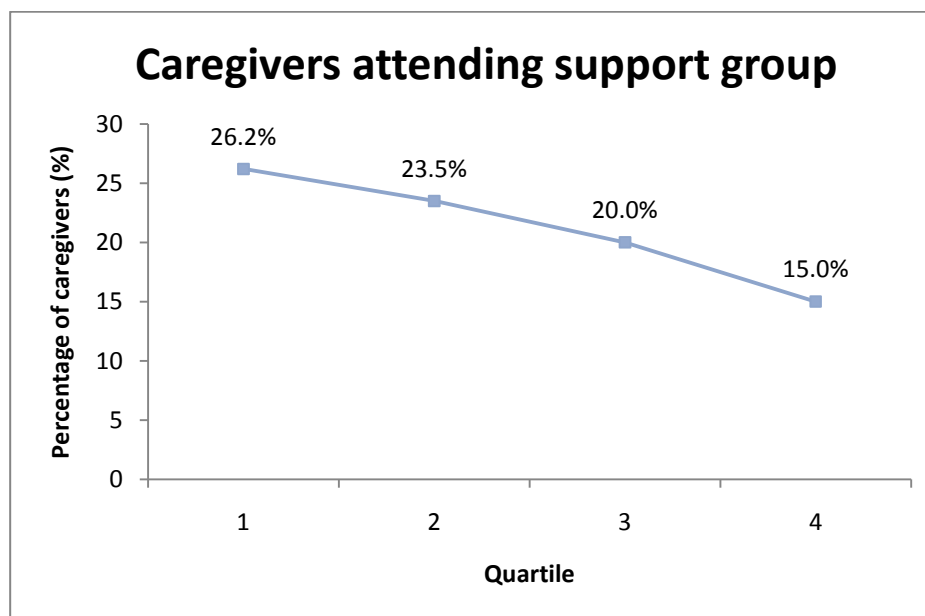


Figure 46: Percentage of caregivers attending support group from baseline to follow-up (diary data)

However, the percentage of caregivers that took advantage of this intervention decreased steadily until the last quartile when only 15% of caregiver still attended the support group.

Diary data of 19 caregivers could be analysed across the entire year. Nine of these caregivers had participated at some point during the year in a support group (47.4%). Using one-way ANOVA no statistically significant differences were observed between the group of caregivers who attended a support group during the year and the group of those who did not attend such a group. However, there was a trend that attendees looked after patients who were less depressed (CSDD) and had less neuropsychiatric and behavioural symptoms (NPI) than non-attendees' relatives as can be seen from data in **Table 56**. Correlation analysis also showed that caregivers of patients with AD were more likely to attend a support group than caregivers of patients with VD or mixed dementia ($r = .472, p = .041$).

Table 56: One-way ANOVA: differences between caregivers utilising support group and those who did not utilise this service during 12 months regarding their QoL outcomes (diary data)

	Caregivers utilising (mean \pm SE)	Caregivers non-utilising (mean \pm SE)	$F_{1,17}$	p
Carers' Group	$n = 9$	$n = 10$		
CSDD	4.11 \pm 1.20	6.80 \pm 1.02	2.96	.103
NPI	8.56 \pm 1.12	17.30 \pm 4.60	3.08	.097

Key. QoL, quality of life; CSDD, Cornell Scale for Depression in Dementia; NPI, Neuropsychiatric Inventory.

The hypothesis listed at the beginning of this chapter (p. 230) that the utilisation of social supports and interventions will improve PWDs' and caregivers' QoL over time was not supported by the data. However, it has to be emphasised that this analysis was based on a limited number of data entries and that there were also some positive trends observed.

Regarding 'day care' the hypothesis was not supported. There was no significant change over time other than patients' illness progression. On the other hand, it was found that caregivers of PWDs using day care showed a trend to have a lower burden score than others. However, this could not be detected as a significant change over time but only as a group difference at follow-up.

Regarding 'sitter service' the hypothesis was also not supported even though there was a trend that patients' functional impairment had decreased at follow-up compared to baseline. However, it is more likely that patients who received a sitter service at baseline and who were more

functionally impaired than others discontinued the study leaving patients who were more able to function independently. Unlike caregivers of patients receiving day care, caregivers looking after PWDs receiving sitter service rated their own QoL lower and rated the patients QoL lower at follow-up compared to others.

PWDs' rate of attending a support group was very small, with only 14.3% at baseline and 5.0% at follow-up. Based on these small numbers no significant differences were observed between PWDs utilising this support option and those who did not utilise it, which means **the hypothesis that a support group for PWDs (Memory Group) would improve patients' or caregivers' QoL over time was not supported.**

The same applies to caregivers' support group. The attendance rate was slightly greater, with 26.2% at baseline and 15.0% at follow-up, but no significant differences were observed. **The hypothesis that a support group for caregivers (Carers' Group) would improve patients' or caregivers' QoL over time was not supported by the data.** However, at follow-up there was a trend that caregivers who attended a support group looked after PWDs who had lower depression and NPI rates. It might be that this is not so much a result of caregivers' support group attendance but rather that those caregivers had to provide less informal caregiving time, which in turn made them feel less burdened and distressed (as shown in chapter 5.8.2.3 [p. 288]), enabling them more easily to participate in such an intervention.

5.7.5 Psychological supports/interventions

Table 57 presents the data collected using the diaries regarding PWDs' utilisation of different counselling options, of which the support provided by social workers of Alzheimers Canterbury was used by more PWDs than any other option. This counselling intervention was also the only one which patients utilised during most of the year as compared to seeing a psychologist or other counsellor.

Table 57: Patient utilisation of counselling from baseline to follow-up (diary data)

	Months 1-3 (n = 42)			Months 4-6 (n = 34)			Months 7-9 (n = 25)			Months 10-12 (n = 20)		
	Patients utilising		Average length of meeting	Patients utilising		Average length of meeting	Patients utilising		Average length of meeting	Patients utilising		Average length of meeting
	n	%	M	n	%	M	n	%	M	n	%	M
Social worker Alzheimers Canterbury	14	33.3	66	2	5.9	111	1	4.0	70	0	0.0	0
Psychologist	2	4.8	210	0	0.0	0	0	0.0	0	0	0.0	0
Other	4	9.5	53	0	0.0	0	0	0.0	0	0	0.0	0

Note. Average utilisation is indicated in minutes unless stated otherwise.

During the first quartile almost every second PWD received some counselling, as shown in **Figure 47** which provides the cumulative percentage of all counselling options. This percentage, however, decreased dramatically within the second quartile and further declined during the second half of the year.

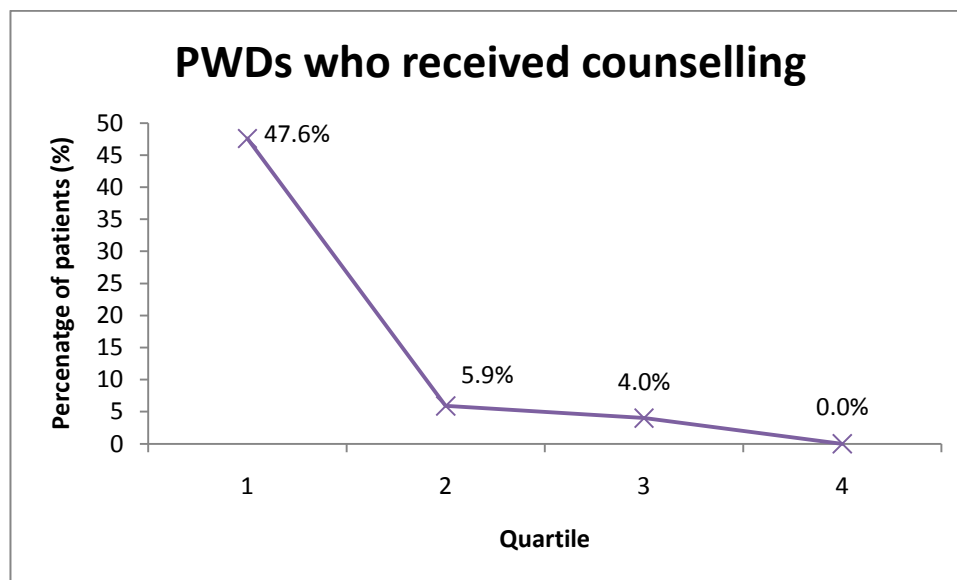


Figure 47: Percentage of PWDs receiving counselling from baseline to follow-up (diary data)

Key. PWDs, persons with dementia.

Figure 48 presents the data on the average length of counselling contacts per PWD per quartile. The average length is here the sum of all counselling options. The 20 patients who received counselling had an average of 329 minutes contact each during the first quartile. The average contact time dropped by about two thirds within the next 3 months and further decreased until the end of the year.

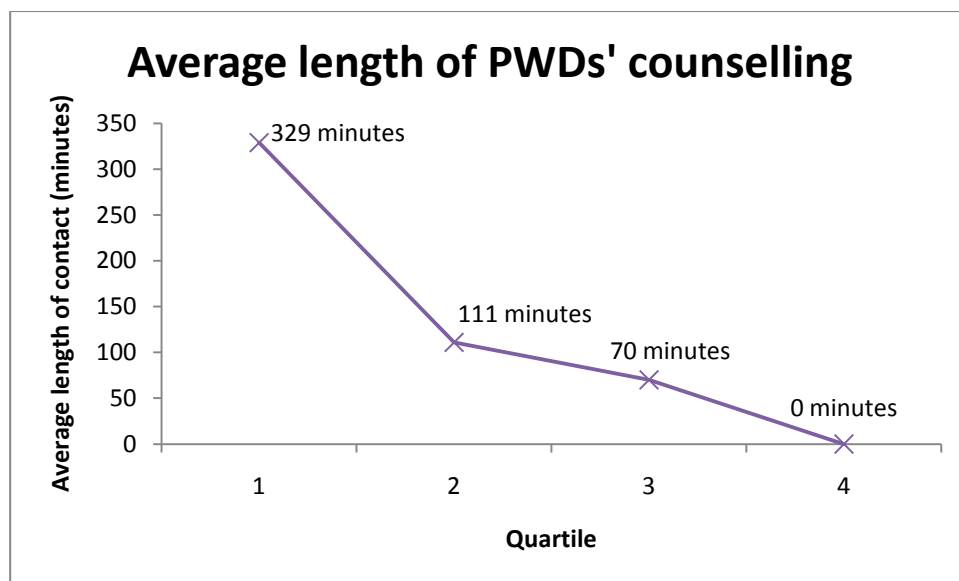


Figure 48: Average length (minutes) of PWDs' counselling contacts from baseline to follow-up (diary data)

Key. PWDs', persons' with dementia.

Diary data of 19 PWDs could be analysed across the entire year. The majority of these patients ($n = 11$) had received counselling at some point during the year (57.9%). Using one-way ANOVA it was found that caregivers of the group of patients who received some counselling during the year felt significantly less burdened than other caregivers ($F_{1,17} = 7.03$, $p = .017$). There was also a trend that those caregivers were less distressed ($F_{1,17} = 4.35$, $p = .052$). Patients who received psychological support from a health professional during the year showed a trend to be less depressed ($F_{1,17} = 2.54$, $p = .129$) and have a better health status ($F_{1,15} = 2.51$, $p = .134$) than patients without counselling support as can be seen from the data in **Table 58**.

Table 58: One-way ANOVA: differences between PWDs utilising counselling and those who did not utilise this intervention during 12 months regarding their QoL outcomes (diary data)

	PWDs utilising (mean \pm SE)	PWDs non-utilising (mean \pm SE)	$F_{1,17}$	p
Counselling	$n = 11$	$n = 8$		
CSDD	4.45 ± 1.11	7.00 ± 1.09	2.54	.129
Comorbidities p	7.18 ± 1.54	11.67 ± 2.62	2.51^1	.134
BI	11.91 ± 2.71	25.25 ± 4.61	7.03	.017
NPI-D	4.18 ± 1.73	9.75 ± 2.03	4.35	.052

Key. PWDs, persons with dementia; QoL, quality of life; CSDD, Cornell Scale for depression in dementia; Comorbidities p health status scale patient rating; BI, Zarit Burden Interview; NPI-D, Neuropsychiatric Inventory-Distress Scale.

¹ $F_{1,15}$

All of the results presented in the table above were confirmed using correlation analysis with the only significant correlation found between patient counselling and caregivers' burden scores ($r = .541, p = .017$).

Table 59 provides an overview of the data obtained from the diaries regarding caregivers' counselling contacts. Similar to PWDs, caregivers also received counselling and advice most often from one of the Alheimers Canterbury social workers. However, this service was only taken up during the first half year, whereas some caregivers saw a psychologist almost throughout the year.

Table 59: Caregiver utilisation of counselling from baseline to follow-up (diary data)

	Months 1-3 (n = 42)			Months 4-6 (n = 34)			Months 7-9 (n = 25)			Months 10-12 (n = 20)		
	Caregivers utilising		Average length of meeting	Caregivers utilising		Average length of meeting	Caregivers utilising		Average length of meeting	Caregivers utilising		Average length of meeting
	n	%	M	n	%	M	n	%	M	n	%	M
Social worker Alheimers Canterbury	11	26.2	81	3	8.8	77	0	0.0	0	0	0.0	0
Psychologist	2	4.8	60	4	11.8	105	1	4.0	240	0	0.0	0
Other	2	4.8	22	0	0.0	0	2	8.0	60	0	0.0	0

Note. Average utilisation is indicated in minutes unless stated otherwise.

Overall, fewer caregivers than patients received counselling during the first quartile. However, the percentage of caregivers utilising this intervention declined less rapidly than the percentage of patients seeing a counsellor (**Figure 49**).

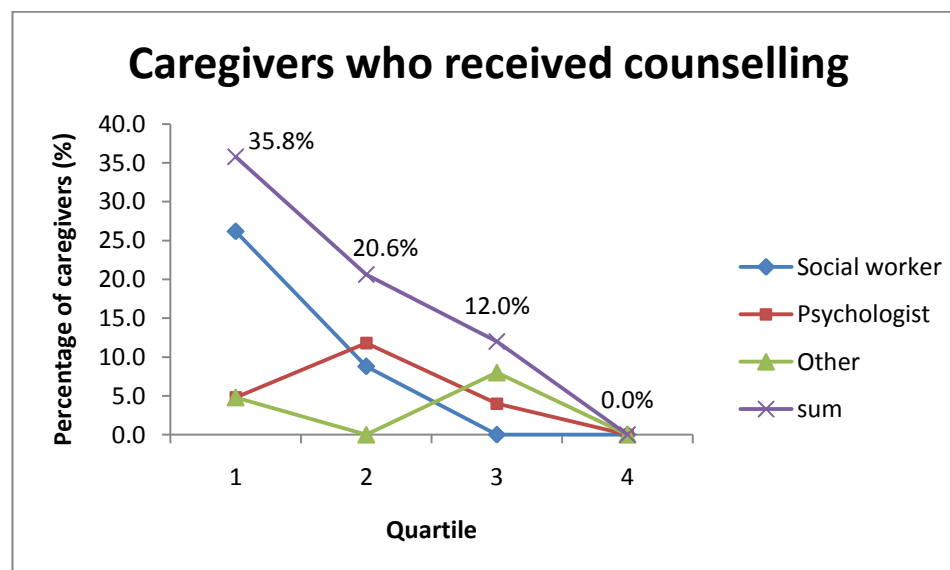


Figure 49: Percentage of caregivers receiving counselling from baseline to follow-up (diary data)

Unlike PWDs, the average length of counselling contacts per caregiver steadily increased (and almost doubled) from 163 minutes during the first 3 months to 300 minutes 6 months later as the figure below illustrates. However, like patients, no caregivers received counselling during the last 3 months of study participation (**Figure 50**).

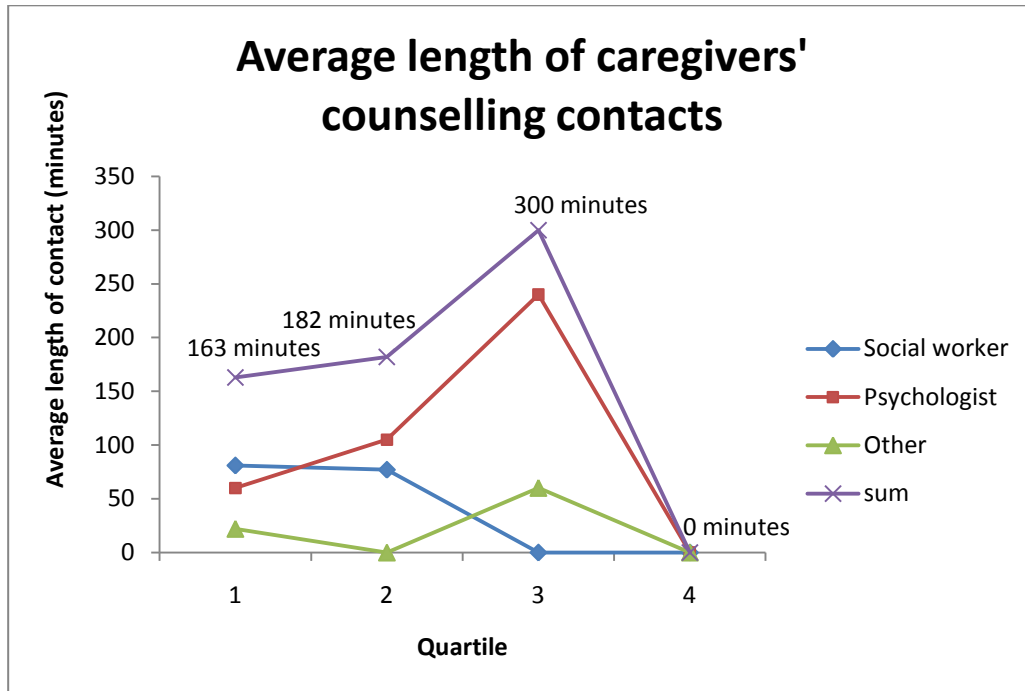


Figure 50: Average length (minutes) of caregivers' counselling contacts from baseline to follow-up (diary data)

It seems unlikely that the need for counselling suddenly diminished and it is more likely that those caregivers who had a high need for this intervention either discontinued the study during the last quartile or they no longer returned the diaries.

Diary data of 19 caregivers could be analysed across the entire year. Ten of these caregivers had received counselling at some point during the year (52.6%). Using one-way ANOVA it was found that caregivers who received some counselling during the 12 months felt significantly more supported by family and friends than those who did not receive any counselling ($F_{1,17} = 6.80$, $p = .018$). There was also a trend that caregivers who did not utilise professional psychological support looked after patients with more (severe) neuropsychiatric and behavioural symptoms ($F_{1,17} = 2.31$, $p = .147$) as can be seen from the data in **Table 60**. Pearson's correlation showed that the MSPSS

significantly correlated with caregivers' counselling utilisation at follow-up ($r = -.535$, $p = .018$) confirming the one-way ANOVA result.

Table 60: One-way ANOVA: differences between caregivers receiving counselling and those who did not utilise this intervention during 12 months regarding their QoL outcomes (diary data)

	Caregivers utilising (mean \pm SE)	Caregivers non-utilising (mean \pm SE)	$F_{1,17}$	p
Counselling	$n = 10$	$n = 9$		
NPI	9.50 \pm 1.11	17.22 \pm 5.23	2.31	.147
MSPSS	73.60 \pm 1.58	63.56 \pm 3.67	6.80	.018

Key. QoL, quality of life; NPI, Neuropsychiatric Inventory; MSPSS, Multidimensional Scale of Perceived Social Support.

In summary, it was found that caregivers of the group of patients who received some counselling during the year felt significantly less burdened than other caregivers. However, linear regression analysis³⁵ showed no significant relationship between patient counselling and caregivers' burden scores at baseline and follow-up. There was also a trend that those caregivers were less distressed. **It was concluded that counselling for patients had a positive impact on caregivers' burden and possibly on distress levels but it did not improve caregivers' burden or QoL.** Patients who received psychological support from a health professional during the year showed a trend to be less depressed and to have a better health status than patients without counselling support. Again, **it was concluded that counselling for patients had a positive impact on patients' depression levels but it did not improve patients' depression or QoL.** Caregiver counselling had a positive impact on caregivers' perceived informal support but it did not improve caregivers' QoL *per se*.

Based on these findings, **the hypothesis** stated at the beginning of this chapter **that the utilisation of psychological supports and interventions will improve PWDs' and caregivers' QoL over time was not supported.**

³⁵ Group numbers between those utilising psychological support and those who did not were too unbalanced to perform two-way ANOVA.

5.7.6 Combined interventions

The following analyses relate to the hypotheses as listed under point 2.e of chapter 3.3 (p. 114):

- combined information and support interventions, such as seminars, day care and counselling, achieve better outcomes, for example PWDs' neuropsychiatric and behavioural symptoms and QoL, than single interventions, such as day care alone;
- caregiver support programmes providing counselling, support and education can improve caregiver QoL;
- non-pharmacological interventions are most effective if they are not only directed at the PWD but also at the caregiver.

Linear regression analysis was performed to determine which (or which combination of) non-medical intervention predicted best QoL in dementia. For PWDs it was found that in a 2-step model the non-utilisation of day care and the utilisation of a support group ('Memory Group') predicted 59.5% of variance of patients' QoL ratings (QOL-ADp) at follow-up (adj. $R^2 = 0.60$, $p < .001$). In a first step, the non-utilisation of day care alone predicted 36.9% of the variance (adj. $R^2 = 0.37$, $p = .004$). Similarly, it was shown that the non-utilisation of day care predicted 50.4% of caregivers' proxy ratings of patient QoL (adj. $R^2 = 0.50$, $p < .001$). The utilisation of non-medical interventions (based on 18 complete sets of data collected using the diaries) could not predict ratings of caregiver QoL (QOL-ADc).

Linear regression analysis showed that there was a negative relationship between an increasing number of interventions (including doctor contacts, hospitalisation, medication, counselling, support group, in-home care, day care, sitter) utilised by PWDs and a decreasing caregiver rating of patients' QoL ($R^2 = 0.114$), as can be seen in **Figure 51**.

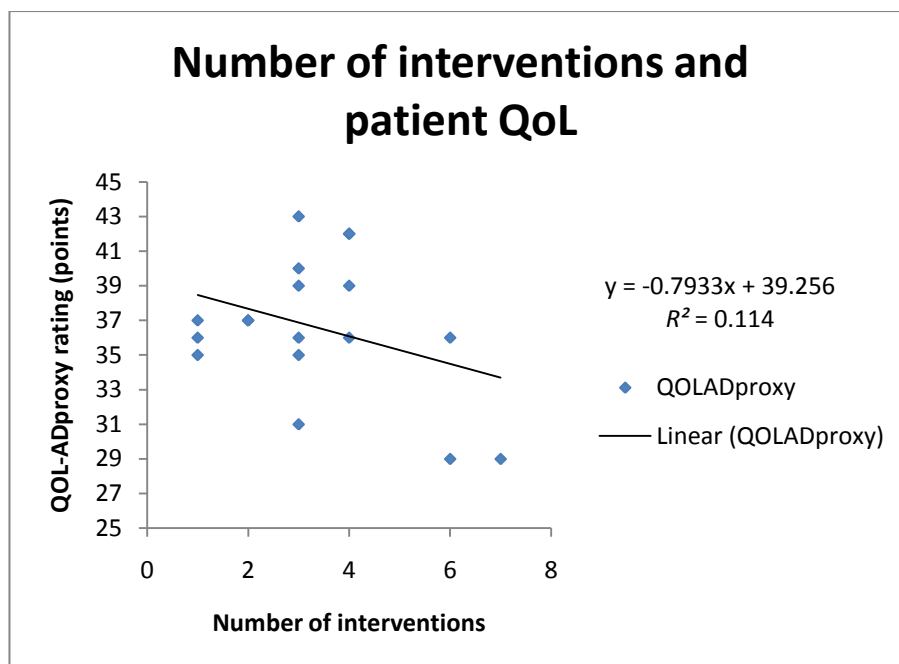


Figure 51: Linear regression between number of patient interventions utilised and QOL-ADproxy ratings (follow-up and diary data)

Figure 52 shows a linear relationship between patients' increasing number of interventions utilised and a progressed stage (CDR) of dementia ($R^2 = 0.310$).

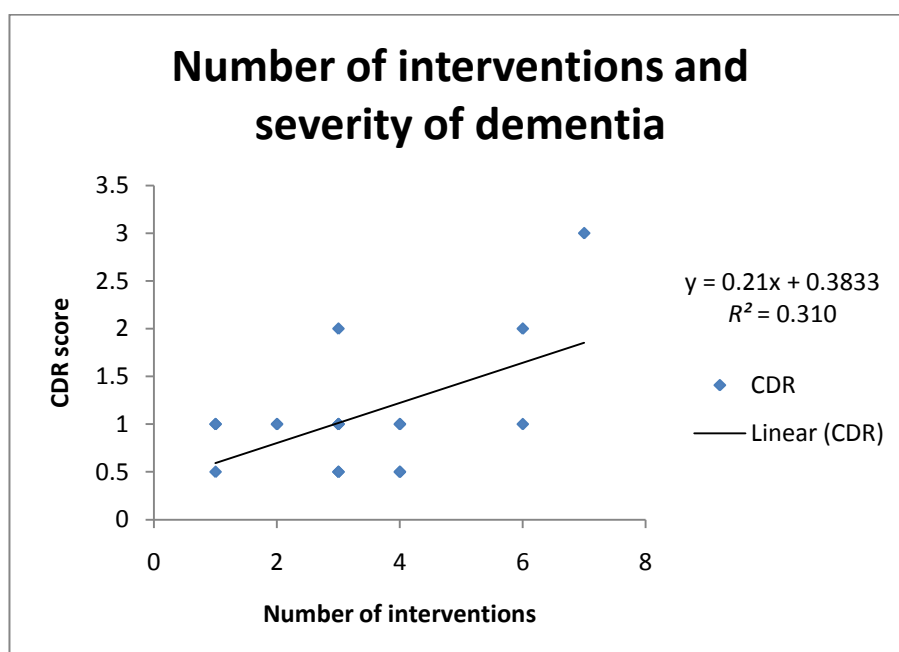


Figure 52: Linear regression between number of patient interventions utilised and CDR scores (follow-up and diary data)

Key: CDR, Clinical Dementia Rating Scale.

The above results indicate that PWDs who utilised more interventions (including doctor contacts, medication, counselling, support group, seminars) were more advanced in their dementia and their QoL was perceived as being lower by their caregivers.

Figure 53 illustrates a positive linear relationship between an increasing number of interventions utilised by caregivers and an increased MSPSS score ($R^2 = 0.135$). It can be concluded that caregivers who took advantage of more interventions during the 12-months period tended to feel more supported by family and friends. This could either be the reason for their utilisation of more interventions or a result of the interventions.

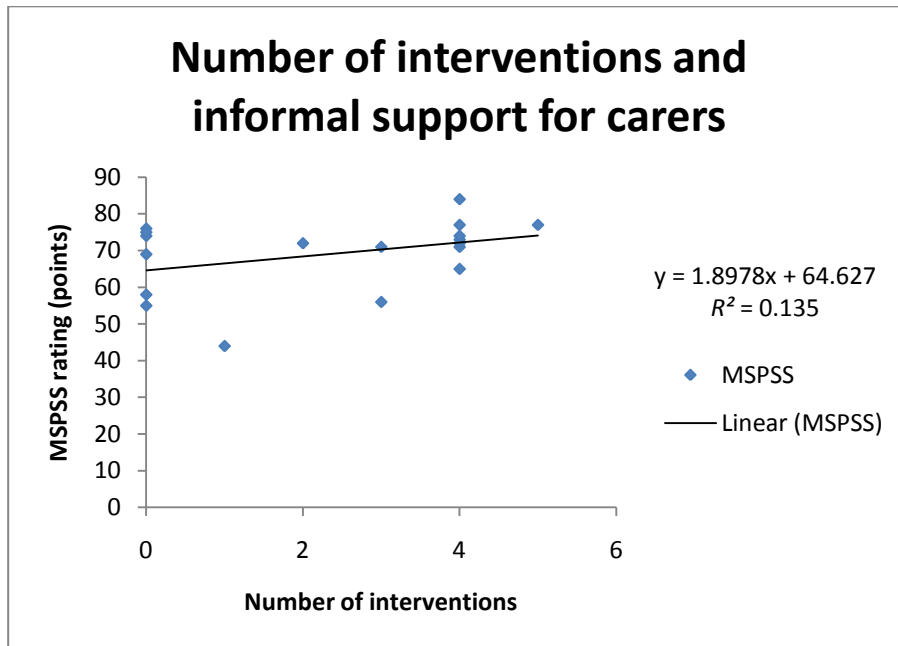


Figure 53: Linear regression between number of caregiver interventions utilised and MSPSS ratings (follow-up and diary data)

Key. MSPSS, Multidimensional Scale of Perceived Social Support

One-way ANOVA analysis comparing groups of PWDs using only one intervention or more than one intervention showed no significant differences. The same also applies to a comparison between caregivers. However, a one-way ANOVA analysis, reducing the number of possible interventions to day care, group support and counselling for PWDs and to seminars, group support and counselling for caregivers, showed some significant differences as can be seen from the data in **Table 61**.

Table 61: One-way ANOVA: differences between PWDs utilising either day care, group support or counselling and those who utilised more than one or none of these interventions during 12 months regarding their QoL outcomes at follow-up (diary data)

	PWDs with 0 intervention (mean ± SE)	PWDs with 1 intervention (mean ± SE)	PWDs with 2 interventions (mean ± SE)	PWDs with 3 interventions (mean ± SE)	$F_{3,14}$	p
Day care, Memory Group, counselling	$n = 6$	$n = 3$	$n = 6$	$n = 3$		
CDR	1.08 ± 0.20	0.83 ± 0.17	0.75 ± 0.11	2.00 ± 0.58	4.20	.026
QOL-ADp	39.50 ± 1.12	37.67 ± 2.03	44.17 ± 0.79	36.00 ± 0.00 ($n = 2$)	8.08^1	.003
QOL-ADproxy	36.17 ± 0.40	38.00 ± 3.61	39.00 ± 1.10	31.33 ± 2.33	3.84	.034
BADLS	10.83 ± 2.39	6.00 ± 3.46	6.33 ± 1.26	25.67 ± 9.96	4.49	.021

Key. PWDs, persons with dementia; QoL, quality of life; QOL-ADp, Quality of Life-Alzheimer Disease Scale patient rating; QOL-ADproxy, Quality of Life-Alzheimer Disease Scale proxy rating; BADLS, Bristol Activities of Daily Living Scale.

¹ $F_{3,13}$

Table 61 shows that PWDs who attended all three types of interventions were at a moderate stage of dementia (CDR score of 2.0), whereas PWDs who used fewer or none of the interventions were at a mild stage of illness (CDR score of around 1.0). The data in **Table 61** also indicate that PWDs who used two interventions had the best mean QoL ratings (patient and caregiver perspective). Further, patients utilising one or two interventions were on average less impaired in their level of daily functioning than patients who did utilise all of the three interventions or none of them.

Table 62 presents data on caregivers' utilisation of the three different interventions. No significant differences were observed. However, the table shows that there was a trend (which did not reach statistical significance) that caregivers who utilised the most interventions had the best QoL and MSPSS ratings. It can be concluded that caregivers who attended educational seminars, support groups and received counselling felt that they had a better QoL and that they were more supported by family and friends than caregiver who utilised fewer or none of these interventions.

Table 62: One-way ANOVA: differences between caregivers utilising either seminars, group support or counselling and those who utilised more than one or none of these interventions during 12 months regarding their QoL outcomes at follow-up (diary data)

	Carers with 0 intervention (mean ± SE)	Carers with 1 intervention (mean ± SE)	Carers with 2 interventions (mean ± SE)	Carers with 3 interventions (mean ± SE)	$F_{3,14}$	p
Seminars, Carers' Group, counselling	$n = 7$	$n = 2$	$n = 2$	$n = 7$		
QOL-ADc	40.43 ± 0.43	37.50 ± 1.50	38.50 ± 0.50	42.57 ± 1.48	2.47	.105
MSPSS	64.43 ± 4.64	71.50 ± 0.50	60.50 ± 4.50	75.43 ± 1.67	2.60	.094

Key. QoL, quality of life; QOL-ADc, Quality of Life-Alzheimer Disease Scale caregiver rating; MSPSS, Multidimensional Scale of Perceived Social Support.

Figure 54 shows that caregivers who had utilised all three interventions (educational seminars, carers' support groups and counselling) were the only ones whose mean QoL ratings improved between baseline and follow-up. However, none of changes between both assessments were statistically significant (matched pair one-way ANOVA analysis).

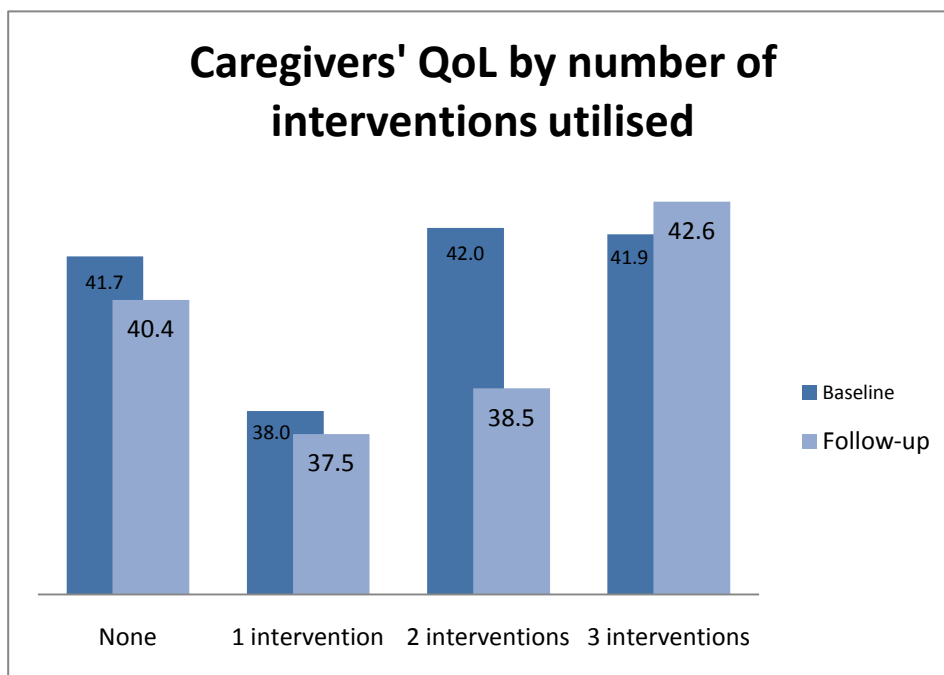


Figure 54: Comparison of mean QOL-ADc values at baseline and follow-up (matched pairs) by number of interventions utilised (seminars, group support or/and counselling) during 12 months (diary data)

Key, QoL, quality of life; QOL-ADc, Quality of Life-Alzheimer Disease Scale caregiver rating.

In summary, after combining medical, educational, social and psychological interventions, the total number of utilised interventions was not a predictor of QoL. However, after reducing the

number of interventions to non-medical supports it was found that combined information and support interventions were linked to significantly better patient QoL than single interventions. **The hypothesis that combined information and support interventions achieve better outcomes than single interventions was supported by the data.** Best outcomes were found for PWDs who utilised a combination of two non-medical interventions. One aspect of the hypothesis, however, was not supported: **combining a number of different interventions did not impact on PWDs' neuropsychiatric and behavioural symptoms.**

The second hypothesis stated that caregiver support programmes providing counselling, support and education can improve caregiver QoL. Indicators were found to support this hypothesis. Caregivers who utilised all three interventions had the best QoL and also felt the most supported by family and friends.

The last hypothesis, that non-pharmacological interventions are most effective if they are not only directed at the PWD but also at the caregiver, could not be determined. None of the formal interventions available in Canterbury is specifically designed to be directed at PWDs and at their caregivers at the same time. However, a significant difference was found between one group, in which only PWDs utilised a non-pharmacological intervention, and another group where PWDs and caregivers utilised an intervention. PWDs' NPI was significantly lower at follow up (one-way ANOVA: $F_{1,16} = 6.88$, $p = .018$) when not only patients but also their caregivers utilised a non-pharmacological intervention (contact with medical professional, seminar, counselling or support group).

5.8 Economic analysis

This section presents the outcomes of the economic evaluation which are related to the study's third research objective: to "measure and describe the direct and indirect costs which are related to steps that PWDs and their family-caregivers take within the New Zealand health system during the disease and which have to be covered by the persons concerned". **Table 63** gives an overview

of the types of costs assessed, the methodologies applied to collect these data and the unit prices which were used to calculate the annual costs. The order in which the cost items are listed in this table is the same order in which the costs were assessed depending on the different instruments utilised to collect these data.

The following hypotheses (as listed under point 3.a of chapter 3.3, p. 114) were evaluated in all four different costs sections: 'Direct medical costs' (p. 278), 'Direct non-medical costs' (p. 285), 'Informal care hours' (p. 288) and 'Indirect costs: productivity costs' (p. 297):

- medical and non-medical costs of PWDs living at home, not including costs of informal caregiving time, increase with the severity of patients' cognitive impairment;
- costs, including indirect costs, increase with increasing dementia severity, increasing behavioural symptoms as well as increasing functional limitations;
- costs increase more with the severity of patients' functional disability than with cognitive impairment.

Table 63: Overview of cost types assessed, unit prices applied and methods of assessment used

Type of costs					QUESTIONNAIRE				DIARY	
			Questionnaire	DIARY	PWD		Carer		PWD	Carer
					Baseline	Follow-up	Baseline	Follow-up	1 year	1 year
Direct medical costs	Medication	ChEIs	NZ \$230.00/monthly prescription	Out-of-pocket	✓	✓	n. a.	n. a.	✓	n. a.
		Mental health	not assessed	Out-of-pocket	not assessed	not assessed	not assessed	not assessed	✓	✓
	Out-of-home-care	GP	NZ \$ 29.00/visit	Out-of-pocket	✓	✓	✓	✓	✓	✓
		Specialist	not assessed	Out-of-pocket	not assessed	not assessed	not assessed	not assessed	✓	✓
		Nurse	not assessed	Out-of-pocket	not assessed	not assessed	not assessed	not assessed	✓	✓
Direct non-medical costs	In-home-care	Meals-on-wheels	NZ \$ 7.72/delivery	not assessed	✓	✓	n. a.	n. a.	not assessed	n. a.
Direct medical costs	Counselling	Psychologist	not assessed	Out-of-pocket	not assessed	not assessed	not assessed	not assessed	✓	✓
		Other	not assessed	Out-of-pocket	not assessed	not assessed	not assessed	not assessed	✓	✓
Direct non-medical costs	Informal care	Care provided by family-caregiver	NZ \$24.85/hour	not assessed	n. a.	n. a.	✓	✓	n. a.	not assessed
Indirect costs	Productivity costs	Lost productivity of caregiver due to care responsibilities	NZ \$90.00/day	NZ \$90.00/day	n. a.	n. a.	✓	not assessed	n. a.	✓
Direct non-medical costs	Other	such as transportation, annual membership Alzheimers Canterbury	not assessed	Out-of-pocket	not assessed	not assessed	not assessed	not assessed	✓	✓

5.8.1 Direct medical costs

This section presents the annual costs of PWDs' and caregivers' mental health medication (5.8.1.1), consultations with health professionals (5.8.1.2) and counselling contacts (5.8.1.3). Additionally, direct medical costs were analysed according to the overall dementia severity (5.8.1.4). If data were collected using both, the questionnaire and the diaries, the results from the questionnaire are outlined first.

5.8.1.1 Medication

The majority of PWDs took either Cholinesterase Inhibitors (ChEIs) or Memantine at baseline and at follow-up at annual costs of NZ \$2,760 per person. The costs per patient considering the entire sample (not just the patients who took medication) increased from NZ \$1,380 at baseline to NZ \$1,553 at follow-up, as can be seen from the data in **Table 55**.

Table 64: Annual costs of dementia medication (ChEIs and Memantine) at baseline and follow-up (questionnaire data)

	Baseline (n = 52)	Follow-up (n = 32)
<i>Dementia medication (ChEIs, Memantine)</i>		
Costs for all utilising patients	\$71,760 (n = 26)	\$49,680 (n = 18)
Mean costs per utilising patient	\$2,760	\$2,760
Mean costs per patient	\$1,380	\$1,553

Key. ChEIs, Cholinesterase inhibitors.

Note. All costs are shown in NZ \$.

Only 1 of the 19 caregivers and 2 of the patients whose diary data could be analysed for the entire year utilised some mental health medication. Since these medications are usually subsidised, no fee or only a small prescription fee of NZ \$3 is charged which is reflected in this data (**Table 65**). The out-of pocket expenses for the dementia medications were 6.5 times lower than the cost calculated based on the retail price. On average, caregivers of patients using ChEIs or Memantine

paid NZ \$924 per annum per patient. The out-of pocket expenses for the entire sample were on average NZ \$584 per patient per year.

Table 65: Annual out-of-pocket expenses for patients' and caregivers' medication (diary data)

	Patients (n = 19)	Caregivers (n = 19)
<i>Dementia medication (ChEIs, Memantine)</i>		
Costs for all utilising participants	\$11,090 (n = 12)	n. a.
Mean costs per utilising participant	\$924	n. a.
Mean costs per participant	\$584	n. a.
<i>Other mental health medication</i>		
Mean costs for all utilising participants	\$34 (n = 2)	\$0 (n = 1)
Mean costs per utilising participant	\$17	\$0
Mean costs per participant	\$2	\$0

Key. ChEIs, Cholinesterase inhibitors.

Note. All costs are shown in NZ \$.

However, these data were based on the diaries returned by 19 caregivers throughout the entire year. The total annual sum can be misleading since not all patients who utilised a dementia medication did so throughout the entire year. For that reason, the **following table** shows what out-of-pocket expenses occurred in every quartile.

Table 66: Out-of-pocket expenses per quartile for patients' dementia medication from baseline to follow-up (diary data)

	Months 1-3 (n = 42)	Months 4-6 (n = 34)	Months 7-9 (n = 25)	Months 10-12 (n = 20)
<i>Dementia medication (ChEIs, Memantine)</i>				
Costs for all utilising participants per quartile	\$6,310 (n = 19)	\$3,964 (n = 11)	\$3,498 (n = 10)	\$2,652 (n = 8)
Mean costs per utilising participant per quartile	\$332	\$477	\$350	\$331
Percentage of participants paying full retail price	26.0%	36.0%	30.0%	37.5%

Key. ChEIs, Cholinesterase inhibitors.

Note. All costs are shown in NZ \$.

Based on these data, caregivers spent on average NZ \$373 on patients' dementia medication every 3 months and a total of NZ \$1,490 per year for those patients who utilised the medication. These data show that on average 1 in 3 patients had to pay the full retail price. Other patients received a price reduction by using their disability allowance.

5.8.1.2 Consultation with health professional

Almost every PWD and the majority of caregivers saw their GPs within the 3 months prior to baseline and follow-up. Consequently, GP visits were a major cost factor in this study. **Table 67** shows that, considering the entire sample, the costs per participant remained relatively stable during the 12-month period with just over NZ \$300 per patient and around NZ \$270 per caregiver per annum.

Table 67: Annual costs of patients' and caregivers' GP visits at baseline and follow-up (questionnaire data)

	Baseline (n = 52)	Follow-up (n = 32)
Patient GP visits		
Costs for all utilising patients	\$17,400 (n = 50)	\$9,744 (n = 28)
Mean costs per utilising patient	\$348	\$348
Mean costs per patient	\$335	\$305
Caregiver GP visits		
Costs for all utilising caregivers	\$14,268 (n = 41)	\$8,700 (n = 25)
Mean costs per utilising caregiver	\$348	\$348
Mean costs per caregiver	\$274	\$272

Key. GP, General Practitioner.

Note. All costs are shown in NZ \$.

The out-of-pocket expenses for GP visits were about one-third lower than the costs calculated on the consultation price, with just over NZ \$200 per patient and around NZ \$150 per caregiver per year for the entire sample. However, **Table 68** also indicates that in addition to the expenses for GP visits significant costs occurred for participants who saw a specialist during the 12-months period: NZ \$96 per patient and NZ \$334 per caregiver per annum. Nurse visits are considerably cheaper than GP consultations, and this is reflected in the data in **Table 68**.

Table 68: Annual out-of-pocket expenses for patients' and caregivers' GP, specialist and nurse contacts (diary data)

	Patients (n = 19)	Caregivers (n = 19)
GP contacts		
Costs for all utilising participants	\$4,023 (n = 18)	\$2,819 (n = 16)
Mean costs per utilising participant	\$224	\$176
Mean costs per participant	\$212	\$148
Specialist contacts		
Costs for all utilising participants	\$1,245 (n = 13)	\$2,337 (n = 7)
Mean costs per utilising participant	\$96	\$334
Mean costs per participant	\$66	\$123
Nurse contacts		
Costs for all utilising participants	\$209 (n = 10)	\$350 (n = 7)
Mean costs per utilising participant	\$21	\$50
Mean costs per participant	\$11	\$18

Key. GP, General Practitioner.

Note. All costs are shown in NZ \$.

5.8.1.3 Counselling

Since the social support counselling provided by the social workers of Alzheimers Canterbury is a free³⁶ service (except for an annual membership fee), the costs calculated here are related to other counselling options such as consultations with Presbyterian Support's psychologists (for which a small fee applies). Since only a small number of participants utilised counselling and because they would have usually been referred to a counsellor through Princess Margaret Hospital, the annual out-of-pocket expenses were quite small as can be seen from the data in **Table 69**.

³⁶ "Free", i.e. no out-of-pocket expenses occurred for the participants. However, these services create costs for the health system from a societal point of view.

Table 69: Annual out-of-pocket expenses for patients' and caregivers' counselling (diary data)

	Patients (<i>n</i> = 19)	Caregivers (<i>n</i> = 19)
Counselling		
Costs for all utilising participants	\$0 (<i>n</i> = 1)	\$90 (<i>n</i> = 4)
Mean costs per utilising participant	\$0	\$23
Mean costs per participant	\$0	\$5

Note. All costs are shown in NZ \$.

5.8.1.4 Direct medical costs according to dementia severity

The following results are related to these hypotheses:

- medical costs of PWDs living at home, not including costs of informal caregiving time, increase with the severity of patients' cognitive impairment;
- medical costs increase with increasing dementia severity, increasing behavioural symptoms as well as increasing functional limitations.

One-way ANOVA showed that the average time of formal care contacts (in-home care, day-care, sitter service) increased between baseline and follow-up but did not reach statistical significance ($F_{1,62} = 3.84, p = .055$). It was therefore decided to base the following correlations on the data collected during follow-up.

The severity of patients' cognitive impairment (3MS score) was not significantly correlated with any of the follow-up care outcomes. However, at baseline, patients' cognitive impairment was correlated with the utilisation of personal care assistance ($r = .354, p = .011$), the number of personal care assistance contacts ($r = -.311, p = .026$) and the average length of personal care assistance contact

($r = -.312, p = .026$). These results indicate that patients who are more cognitively impaired were more likely to receive personal care assistance. More impaired PWDs also received more and longer formal care contacts within the 2 weeks prior to baseline assessment.

The severity of patients' dementia (CDR score) was significantly correlated with:

- utilisation of personal care assistance ($r = -.572, p = .001$),
- number of personal care assistance contacts ($r = .521, p = .002$),
- average length of personal care assistance contact ($r = .604, p < .001$),
- hospitalisation ($r = -.404, p = .022$),
- number of nights in hospital ($r = .361, p = .043$).

Similar to more cognitively impaired patients, those who were more progressed in their dementia also were more likely to receive assistance with personal care and hygiene during more and longer contacts. These PWDs were also more likely to be hospitalised and for a longer period of time than less progressed patients.

Patients' frequency and severity of neuropsychiatric and behavioural symptoms (total NPI score) were significantly correlated with patients' utilisation of mental health drugs ($r = -.481, p = .005$), but not with the utilisation of ChEIs. This correlation shows that patients with more and more severe neuropsychiatric and behavioural symptoms were likely to have been prescribed mental health medication such as anti-depressants.

PWDs' level of functional impairment (BADLS score) was significantly associated with:

- utilisation of personal care assistance ($r = -.562, p = .001$),
- number of personal care assistance contacts ($r = .537, p = .002$),
- average length of personal care assistance contact ($r = .625, p < .001$),
- caregivers' utilisation of GP and/or medical specialist care ($r = -.359, p = .043$).

Again, as for cognition and dementia severity, patients' functional status also influenced the utilisation of personal care assistance. Having a lower level of daily functioning increased the likelihood of patients receiving personal care assistance and having more and longer contacts. Interestingly, caregivers of patients with more impairment were also significantly more likely to see their GP or a medical specialist.

Based on these findings the hypothesis that medical costs of PWDs living at home increase with the severity of patients' cognitive impairment could not be determined. However, the results suggest that patients' increasing cognitive impairment might increase direct medical costs.

The hypothesis that medical costs increase with increasing dementia severity, increasing behavioural symptoms as well as increasing functional limitations was supported by the data.

5.8.2 Direct non-medical costs

5.8.2.1 Meals-on-wheels and out-of-pocket expenses

Approximately 1 in 10 PWDs received meals-on-wheels. With an average delivery price of NZ \$8 (rounded off) per meal the annual costs for this sample were NZ \$463 at baseline and NZ \$278 at follow-up. The costs per utilising patient were just under NZ \$100 per year (see **Table 70**).

Table 70: Annual costs of patients' meals-on-wheels at baseline and follow-up (questionnaire data)

	Baseline (n = 52)	Follow-up (n = 32)
<i>Meals-on-wheels</i>		
Costs for all utilising patients	\$463 (n = 5)	\$278 (n = 3)
Mean costs per utilising patient	\$93	\$93
Mean costs per patient	\$9	\$9

Note. All costs shown in NZ \$.

In addition to meals-on-wheels, there were other out-of-pocket expenses related to patients' and caregivers' health. For the most part, these expenses were for transportation, for example to and

from doctor-appointments, for the annual membership fee of Alzheimers Canterbury and for prescription costs for medications other than dementia or mental health drugs. As can be seen from the data in **Table 71**, the majority of participants had to cover such non-medical out-of-pocket expenses. Costs were higher for PWDs than for caregivers with an average of just over NZ \$150 per utilising patient and of about NZ \$110 per utilising caregiver. However, considering the entire sample, additional out-of-pocket expenses were twice as high for patients as for caregivers per annum (**Table 71**).

Table 71: Annual direct non-medical out-of-pocket expenses for patients and caregivers (diary data)

	Patients (n = 19)	Caregivers (n = 19)
<i>Other out-of-pocket expenses</i>		
Costs for all utilising participants	\$2,508 (n = 16)	\$1,247 (n = 11)
Mean costs per utilising participant	\$157	\$113
Mean costs per participant	\$132	\$66

Note. All costs are shown in NZ \$. Costs include transportation, annual membership Alzheimer Society and prescription costs for medications other than dementia or mental health drugs.

5.8.2.2 Direct non-medical costs according to dementia severity

The following results are related to these hypotheses:

- non-medical costs of PWDs living at home, not including costs of informal caregiving time, increase with the severity of patients' cognitive impairment;
- non-medical costs increase with increasing dementia severity, increasing behavioural symptoms as well as increasing functional limitations.

The severity of patients' cognitive impairment (3MS score) was not significantly correlated with any of the follow-up or baseline non-medical care outcomes.

The severity of patients' dementia (CDR score) was significantly correlated with:

- utilisation of domestic care assistance ($r = -.368, p = .029$),
- number of domestic care assistance contacts ($r = .491, p = .017$),
- utilisation of day care ($r = -.350, p = .049$),
- number of day care contacts ($r = .472, p = .006$),
- average length of day care contacts ($r = .371, p = .036$),
- utilisation of sitter service ($r = -.544, p = .001$),
- number of sitter service contacts ($r = -.474, p = .006$).

These correlations indicate that participants with more severe dementia were more likely to receive domestic assistance and also to be more often supported in their household tasks. These PWDs were also more likely to attend day care and to attend day care more often and on average longer than patients with less progressed dementia. Additionally, these patients were more likely to utilise a sitter service and also to receive sitter service more often.

Patients' frequency and severity of neuropsychiatric and behavioural symptoms (total NPI score) was significantly correlated with patients' number of day care contacts ($r = .398, p = .024$) and sitter service contacts ($r = -.424, p = .016$). These results allow the conclusion that patients with more and more severe neuropsychiatric and behavioural symptoms attended day care more often within the 2 weeks prior to follow-up than other patients. However, at the same time these participants also had fewer sitter service contacts.

PWDs' level of functional impairment (BADLS score) was significantly associated with:

- utilisation of domestic care assistance ($r = -.350, p = .050$),
- number of domestic care assistance contacts ($r = .493, p = .004$),
- utilisation of day care ($r = -.426, p = .015$),
- number of day care contacts ($r = .547, p = .001$),

- average length of day care contacts ($r = .444$, $p = .011$).

Again, as for dementia severity, patients' functional status influenced the utilisation of domestic care assistance. Having a lower level of daily functioning increased the likelihood of patients receiving domestic care assistance and having more contacts. PWDs who were functionally more impaired attended day care more often within a fortnight and these contacts lasted on average longer than for patients who were less functionally impaired.

Based on these findings, the hypothesis that direct non-medical costs of PWDs living at home, not including costs of informal caregiving time, increase with the severity of patients' cognitive impairment was not supported. However, the second hypothesis which stated that direct non-medical costs, not including costs of informal caregiving time, increase with increasing dementia severity, increasing behavioural symptoms as well as increasing functional limitations was supported by the data.

Overall, the stage of dementia (CDR) as well as the level of functional impairment were the best predictors of an increase in formal care utilisation and consequently of an increase in direct costs (not informal care). **The hypothesis that costs increase more with the severity of patients' functional disability than with patients' cognitive impairment was supported by the data.** However, most of the increased expenditures were supports and interventions covered by the health system. This means that these increased costs affect patients or caregivers relatively little but are important for the health system from a societal point of view.

5.8.2.3 Informal care hours

The following results relate to the following hypotheses (as listed under point 3b of chapter 3.3, p. 114):

- Family and friends spend considerably more time providing care for the PWD than receiving formal support for their own health needs.

- These caregiving hours have a significant negative impact on caregivers' physical and psychological health which consequently also negatively impacts patients' QoL.

The hypothesis that direct non-medical costs increase with increasing dementia severity, increasing behavioural symptoms as well as increasing functional limitations is also discussed here in relation to informal care hours.

Using the replacement wage method, unpaid care provided by the family-caregivers was calculated for baseline and follow-up data. In this approach, the unit cost of unpaid caregiving time was the hourly wage of a worker who would need to be hired to provide the same care that an unpaid family-caregiver is providing (Murman, et al., 2002). In Economics, it is more common to use the concept of opportunity costs. That is, how much the caregiver would be earning if he/she worked for pay instead of taking care of the PWD. However, as discussed in the methodology chapter, the replacement wage method was chosen despite these considerations since it could be expected that a majority of caregivers in this study would be spouses who would no longer be part of the workforce.

The carer rate of NZ \$24.85 per hour was adopted from the 2008 NZ economic dementia report (Access Economics, 2008). The informant was asked to estimate the time spent in a typical day for different categories of care that were new since the onset of dementia. The time spent in each of the categories and services was summed and then annualised. The following table summarises how much time was spent on average on each care category per PWD per day. Overall, 3 in 4 PWDs received assistance in their daily living activities from their family-caregiver and/or were supervised. A slightly smaller percentage of patients received informal care at follow-up (75.0%) as compared to baseline (78.8%).

As can be seen from the data in **Table 72**, all caregivers together provided 324.3 hours at baseline and 194.0 hours at follow-up of informal care in a typical day. This is an average of 6.2 hours at baseline and 6.1 hours at follow-up per PWD considering the entire sample ($n = 52$ and $n = 32$ respectively).

Supervision was by far the most time-consuming care activity with more than 10 hours on average per PWD in a typical day. Supervision included that the caregiver prevented the PWD from getting lost, from wandering off or from getting into some kind of difficulty. A significant amount of time, almost one and a half hours per day, was spent on taking the PWD to various places other than grocery shopping for example to the doctor (**Table 72**).

Constant supervision during the day was required for 12 PWDs (23.1%) at baseline and for 9 PWDs (28.1%) at follow-up. Of those who needed supervision all day, there were 7 at baseline and 4 PWDs 12 months later who also needed supervision at night (i.e., 24 hour care). For PWDs who required constant day supervision, a limit of 16 hours care per day was imposed to allow for 8 hours of sleep (Langa, et al., 2001). Other caregiving activities were then deducted from 960 minutes and the result used to determine the time spent on supervision alone. The same method was applied to those patients who required 24 hour care. Here the other caregiving tasks were deducted from 1,440 minutes (24 hours) resulting in the time spent on supervision (**Table 72**).

Table 72: Informal care hours at baseline and follow-up (questionnaire data)

		Baseline (n = 52)	Follow-up (n = 32)
		Total	
Caregivers who provided unpaid care	<i>n</i>	41	24
	%	78.8	75.0
Total informal care time provided by all caregivers per day	<i>M (minutes)</i>	19,456	11,640
	<i>M (hours)</i>	324.3	194.0
Average informal care time per patient (receiving care) per day	<i>M (minutes)</i>	475	485
	<i>M (hours)</i>	7.9	8.1
Average informal care time per patient per day	<i>M (minutes)</i>	374.2	363.8
	<i>M (hours)</i>	6.2	6.1
		Supervision	
Patients who received assistance	<i>n</i>	26	14
	%	50.0	43.8
Average time per patient in a day	<i>M (minutes)</i>	619	659
		Transportation	
Patients who received assistance	<i>n</i>	28	17
	%	53.8	53.1
Average time per patient in a day	<i>M (minutes)</i>	82	70
		Dressing	
Patients who received assistance	<i>n</i>	12	11
	%	23.1	34.4
Average time per patient in a day	<i>M (minutes)</i>	23	20
		Eating	
Patients who received assistance	<i>n</i>	14	17
	%	26.9	53.1
Average time per patient in a day	<i>M (minutes)</i>	34	50
		Looking after patient's appearance	
Patients who received assistance	<i>n</i>	19	13
	%	36.5	40.6
Average time per patient in a day	<i>M (minutes)</i>	16	12

Note. Care time was corrected for patients requiring constant supervision during day, or day and night so that the total care time was not more than 1440 minutes (24 hrs).

Table 72 shows also that all caregivers together provided 324.3 hours at baseline and 194.0 hours at follow-up of informal care in a typical day. This translate into NZ \$8,059 worth of informal care at baseline (324.3 hrs * NZ \$24.85) and NZ \$4,821 at follow-up (194.0 hrs * NZ \$24.85). With respect to the entire sample, at baseline the value of informal unpaid caregiving hours was on average NZ \$154 per day per patient (6.2 hours * NZ \$24.85) at baseline.

At follow-up this number slightly decreased, to NZ \$152 per day per patient (6.1 hours * NZ \$24.85). However, considering only patients who actually received informal care from their families and friends, the average number of hours slightly increased from 7.9 at baseline to 8.1 at follow-up, with an increase of informal care costs from NZ \$196 to NZ \$201 per patient per day.

Table 73 gives a brief overview of daily the informal care costs calculated for this sample based on baseline and follow-up data.

Table 73: Daily informal care costs at baseline and follow-up (questionnaire data)

	Baseline (n = 52)	Follow-up (n = 32)
Daily informal care costs		
Costs for all caregivers providing unpaid care	\$8,059 (n = 41) (= 78.8% of 52)	\$4,821 (n = 24) (= 75.0% of 32)
Mean costs per caregiver providing unpaid care	\$197	\$201
Mean costs per caregiver based on entire sample	\$155	\$151

Note. All costs are shown in NZ \$.

These daily informal care costs translate into substantial annual costs. Based on the baseline data, this sample provided informal care worth NZ \$2.94 million (NZ \$8,059 * 365 days) and NZ \$1.76 million based on follow-up data (NZ \$4,821 * 365 days). **Table 74** presents the informal care costs occurring during 12 months.

Table 74: Annual informal care costs at baseline and follow-up (questionnaire data)

	Baseline (n = 52)	Follow-up (n = 32)
Annual informal care costs		
Costs for all caregivers providing unpaid care	\$2,941,170 (n = 41)	\$1,759,629 (n = 24)
Mean costs per caregiver providing unpaid care	\$71,744	\$73,318
Mean costs per caregiver based on entire sample	\$56,567	\$54,988

Note. All costs are shown in NZ \$.

Using the baseline data, it can be calculated that 1,992 caregivers in Canterbury (78.8% of 2,528 carers) provide together on average 15,736.8 hours of unpaid care per day (1,992 carers * 7.9 hrs). This is a total of 5,602,300.8 hours p.a. (15,736.8 hrs * 356 days) with a value of NZ \$139.2 million per year. This is a rather conservative calculation, since this sample consisted of 83% of persons with mild dementia. But with the need for informal care increasing with illness progression (Figure 55, p. 296), more average hours per day and higher costs could be expected for a sample including more patients at a later stage of dementia.

Extrapolating from the follow-up data, there are 1,896 persons in **Canterbury** caring for a PWD at home (75.0% of 2,528 carers). They together work an average of 15,357.6 hours of unpaid care per day (1,896 carers * 8.1hrs) and a total of 5,467,305.6 hours per year. **This unpaid care has an annual value of NZ \$135.8 million.**

In order to answer the question if family and friends spent considerably more time providing care for the PWD than receiving formal care for their own health needs, caregivers' formal care time was summarised (see **Table 75**). On average, caregivers received 1,120.6 hours of formal care and support per caregiver per annum.

Table 75: Average annual formal care time received by family-caregivers (diary and questionnaire data)

	Minutes (Mean)	Hours (Mean)
Formal care received per caregiver p.a.		
Hospitalisation	36,432	607.2
GP	214	3.6
Specialist	449	7.5
Nurse	164	2.7
Educational seminars	630	10.5
Respite: day care	17,706	295.1
Respite: sitter service	10,140	169.0
Support group	852	14.2
Counselling	645	10.8
Total	67,232	1,120.6

Key. GP, general practitioner.

Since family caregivers provided an average of 2,263 hours of unpaid care to the PWDs annually (Table 76), they provided more than twice as many hours of informal care than they received formal care for their own health needs.

Table 76: Average annual informal care time provided by family-caregivers (baseline-questionnaire data)

	Minutes (Mean)	Hours (Mean)
Informal care provided per patient		
Per day	372	6.2
Per annum	135,780	2,263

Based on these findings, the hypothesis that family and friends spend a considerably greater amount of time providing care for the PWD than receiving formal support for their own health needs was supported.

Another question was if these caregiving hours had a significant negative impact on caregivers' physical and psychological health, which would also negatively impact patients' QoL. Pearson's correlation analysis showed the following baseline associations between the time spent on informal care and:

- stage of illness ($r = .288, p = .036$),
- PWDs' QoL: patient ratings ($r = -.374, p = .006$),
- PWDs' depressive symptoms ($r = .328, p = .017$),
- neuropsychiatric and behavioural symptoms ($r = .273, p = .048$),
- level of daily functioning ($r = .561, p < .001$),
- caregivers' level of burden ($r = .369, p = .007$),
- caregivers' level of distress ($r = .334, p = .015$),
- length of formal care contacts ($r = .566, p < .001$).

These results indicate that PWDs at a later stage had a significantly higher need for informal care (**Figure 55**). Patients who showed more depressive, neuropsychiatric and behavioural symptoms and were more functionally impaired required also more informal care hours. Patients who received more informal care were more likely to rate their QoL lower. Caregivers of those patients were more likely to feel burdened and distressed than other caregivers. Interestingly, there was no correlation between informal care and caregivers' QoL beyond these QoL indicators (BI and NPI-D). However, there was a trend for a correlation between informal care time and caregivers' depression levels at baseline ($r = .250, p = .071$) and at follow-up ($r = .318, p = .076$). An increase in informal care was often linked to an increase in formal care time as well. **The hypothesis that the costs of informal caregiving hours increase with increasing dementia severity, increasing behavioural symptoms as well as increasing functional limitations was supported.**

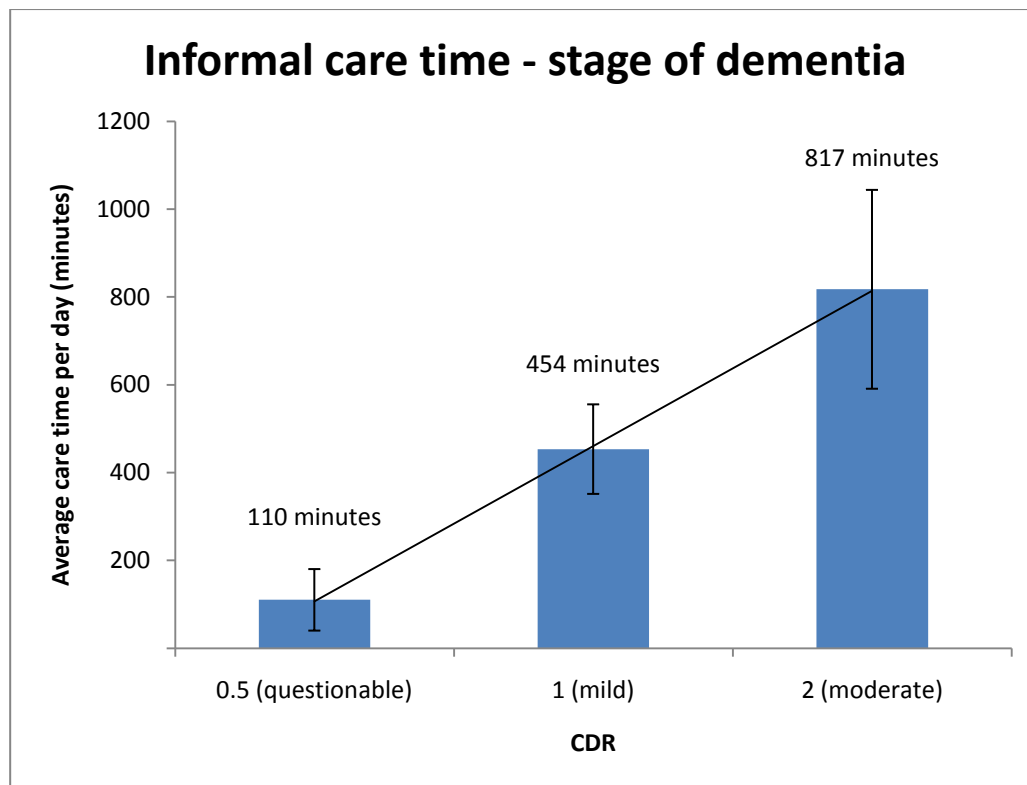


Figure 55: Informal care time according to severity of dementia at baseline (questionnaire data)

At follow-up, the following significant correlations with time spent on informal care were observed:

- stage of illness ($r = .531, p = .002$),
- PWDs' QoL: proxy ratings ($r = -.366, p = .039$),
- neuropsychiatric and behavioural symptoms ($r = .482, p = .005$),
- level of daily functioning ($r = .708, p < .001$),
- PWDs' health status: patient ratings ($r = .402, p = .003$),
- PWDs' health status: proxy ratings ($r = .402, p = .003$).

It can be concluded from these results that at follow-up, PWDs at a later stage and PWDs with more neuropsychiatric and behavioural symptoms and a lower level of functioning still (like at baseline) had a significantly higher need for informal care. However, unlike at baseline, not PWDs themselves but their caregivers considered patients' QoL lower if they required more care. Both PWDs and caregivers agreed that PWDs required more informal care if they had more health problems in addition to the dementia than other patients with a better health status.

Based on these findings, the hypothesis that caregiving hours have a significant negative impact on caregivers' physical health was not supported by the data. Nevertheless, the second part of the hypothesis that informal care has a significant negative impact on caregivers' psychological health which would also negatively impact patients' QoL was supported, but only based on baseline data.

5.8.3 Indirect costs: productivity costs

The following results relate to the hypothesis as listed under point 3.c of chapter 3.3 (p. 114) that indirect costs increase with increasing dementia severity, increasing behavioural symptoms as well as increasing functional limitations and decreasing cognitive abilities.

The productivity costs (lost productivity of a family-caregiver due to the care of a relative or friend with dementia) were assessed using the relevant part of the RUD at baseline as well as the cost diaries during the 12 month period between baseline and follow-up. At follow-up, two questions regarding caregivers' work status were included into the evaluation. Productivity costs were calculated at NZ \$90.00 per day of work loss³⁷.

5.8.3.1 Productivity costs according to baseline data

Table 77 shows that at baseline, close to 40% of caregivers were in paid employment. The majority of these caregivers (71.4%) were able to work without having to take time off to care for the PWD during the 2 weeks prior to the interview. However, almost one-third (28.6%) of those in paid employment could not work up to 6 days during the 2 weeks prior to the assessment because they had to care for the PWD (**Table 77**). This is an average of 0.6 days per caregiver within 2 weeks (12 days * divided by 21 caregivers in paid employment).

³⁷ Please refer to section 10.2 of the methodology chapter for further explanation.

Table 77: Caregiver work status and days of work loss (productivity costs) at baseline (questionnaire data)

		<i>n</i>	%
Being in paid employment	Yes	21	39.6
	No	32	60.4
Days of work loss during 2 weeks prior to baseline interview	0	15	71.4
	1	4	19.0
	2	1	4.8
	6	1	4.8
} 28.6%			
Average days of work loss per employed caregiver during 2 weeks prior to baseline	<i>M</i>	0.6	

Based on these data alone, **the productivity costs for this sample were in total NZ \$29,484 per year** (0.6 days * 26 weeks * NZ \$90 per lost day of work * 21 caregiver in paid employment). This equals annual mean productivity costs of NZ \$1,404 per caregiver in employment and costs of NZ \$556 per caregiver considering the entire sample (**Table 78**).

Table 78: Annual productivity costs at baseline (questionnaire data)

Baseline (<i>n</i> = 53)	
<i>Productivity costs</i>	
Costs for all employed caregivers	\$29,484 (<i>n</i> = 21)
Mean costs per employed caregiver	\$1,404
Mean costs per caregiver	\$556

Note. All costs are shown in NZ \$.

It was calculated that in Canterbury approximately 1,435 persons with mild dementia, 732 with moderate dementia and 361 with severe dementia were cared for at home during the time this study was conducted (Table 18, p. 167)

Given the relatively high level of representativeness of this study (section 5.1, p. 165), it can be estimated that about 1,001 family-caregivers of PWDs were in paid employment at the time of the data collection (2,528 PWDs at home * 39.6% of caregivers who were in paid employment). If an average of 28.6% of these caregivers ($n = 286$) could not work for an average 0.6 days within 2 weeks, then **the total lost productivity costs for Canterbury was NZ \$401,544 per annum** during the time of data collection (0.6 days * 26 weeks * NZ \$90* 286 caregivers).

Pearson's correlation showed no significant relationship between caregivers' number of days of lost productivity and patients' stage of illness (CDR score: $r = -.019$, $p = .896$), behavioural symptoms (NPI: $r = .171$, $p = .227$), functional impairment (BADLS score: $r = .026$, $p = .855$) or cognitive impairment (3MS score: $r = .008$, $p = .974$) at baseline. The means of days of work loss depending on any of these four outcomes showed no clear upwards or downwards trend. **The hypothesis that indirect costs increase with dementia severity and behavioural symptoms as well as with decreasing functional and cognitive abilities was not supported by the data.** However, it has to be taken into consideration that there were probably not enough participants enrolled in this study to split the data into meaningful groups and that the analysis and the conclusions that could be drawn from it were limited.

Also, the number of days of work loss during the 2 weeks prior to baseline interview were negatively correlated with patients' hospitalisation during the same period of time ($r = -.395$, $p = .004$). This indicates that it was more likely that caregivers had to take time off from work if the PWD they looked after was hospitalised.

5.8.3.2 *Productivity costs according to data from the cost diaries*

In their diaries, caregivers were asked to complete weekly data on days of work loss due to care for the PWD. They were asked to fill in the number of days (including 0.5 days) and the reason, such as taking the PWD to a hospital.

Data collected using the diaries show that the number of days caregivers had to take off due to their care responsibilities varied over the duration of 1 year. **Table 79** indicates that of those caregivers who were in paid employment, 40.5% were on average not able to work for 2.4 days during the first 3 months (0.4 days per fortnight) and for 0.6 days during the second quartile (0.1 days per fortnight). No days of work loss occurred during the third and fourth quartile in this sample. The average number per quartile for the entire year was 0.75 days of work loss (0.125 days per fortnight). Based on the diary data, the average percentage of caregivers in employment was 29.2% as compared to 39.6% at baseline-assessment (questionnaire).

Table 79: Caregiver work status and days of work loss from baseline to follow-up (diary data)

Months 1-3 (n = 42)			Months 4-6 (n = 34)			Months 7-9 (n = 26)			Months 10-12 (n = 20)		
Participants employed		Average days of work loss per employed participant	Participants employed		Average days of work loss per employed participant	Participants employed		Average days of work loss per employed participant	Participants employed		Average days of work loss per employed participant
n	%	M	n	%	M	n	%	M	n	%	M
17	40.5	2.4	13	38.2	0.6	6	23.1	0.0	3	15.0	0.0

These observations show that the earlier cost calculations based on the questionnaire data have to be treated with caution, especially when applied to annual estimates. Based on the diary data, **the productivity costs for this sample were in total NZ \$4,374 per year** (2.4 days * NZ \$90 per lost day of work * 17 caregivers in paid employment + 0.6 days * NZ \$90 per lost day of work * 13 caregiver in paid employment). This equals annual mean productivity costs of NZ \$14,688 based on the data collected during the first quartile and NZ \$2,808 based on the second quartile. Since none of the caregivers who provided diary information during the third and fourth quartile had to take time off from work due to their caregiving responsibilities, there were no productivity costs during these months (**Table 80**).

Table 80: Productivity costs per quartile from baseline to follow-up (diary data)

	Months 1-3 (n = 42)	Months 4-6 (n = 34)	Months 7-9 (n = 26)	Months 10-12 (n = 20)
Productivity costs				
Costs for all employed caregivers per quartile	\$3,672 (n = 17)	\$702 (n = 13)	\$0 (n = 6)	\$0 (n = 3)
Mean costs per employed caregiver per quartile	\$216	\$54	\$0	\$0
Mean costs per caregiver per quartile	\$87	\$21	\$0	\$0
Mean costs per caregiver per annum	\$350	\$83	\$0	\$0
Total costs per annum	\$ 14,688	\$2,808	\$0	\$0

Note. All costs are shown in NZ \$.

5.8.3.3 Caregiver work status at follow-up

During the baseline interview, it became apparent that the two questions regarding loss of working time due to caregiving responsibilities might not adequately reflect the caregivers' situation because some had already cut back their work hours to accommodate the PWD's needs. It was therefore decided to include the relevant part of the RUD at follow-up. RUD data were collected from the sample of 33 caregivers who completed the follow-up assessment and 10 caregivers who provided information after their relatives had moved into residential care. Fifteen of these 43 caregivers (34.9%) had been working for the whole period between baseline and follow-up assessment an average of 25.5 hours each per week. None of these hours was paid care which caregivers provided for the PWDs. One caregiver (6.7%) cut her weekly hours down from 30 to 22 to care for the PWD. All other caregivers sustained their number of working hours from baseline to follow-up assessment. Two of these 43 caregivers had stopped working completely since baseline and in one of the two cases the primary reason for this decision was the caregiver's own problematic health status.

5.8.4 Total annual costs

Table 81 summarises the total average annual costs per study participant for patients as well as for caregivers. The table shows that the value of unpaid care hours contributed by far the most to the total patient related costs of NZ \$58,500 per year (based on baseline data). Costs remained stable during 12 months. However, it has to be taken into consideration that a number of cost factors had not been assessed for this study. The data also show that about half of patients' direct costs (not considering informal care) and three quarters of caregivers' direct costs were covered by participants themselves (out-of-pocket).

Table 81: Summary of mean annual costs per PWDs and caregivers (questionnaire and diary data)

Mean annual costs per PWD/caregiver		PWD		Caregiver	
		Baseline	Follow-up	Baseline	Follow-up
Medication	ChEIs	\$1,380	\$1,552	n. a.	n. a.
	Mental health*	\$2	\$2	\$0	\$0
Out-of-home-care	GP	\$335	\$305	\$274	\$272
	Specialist*	\$66	\$66	\$123	\$123
	Nurse*	\$11	\$11	\$18	\$18
Counselling	Psychologist and other*	\$0	\$0	\$5	\$5
In-home-care	Meals-on-wheels	\$9	\$9	n. a.	n. a.
Other out-of-pocket expenses	for example transportation*	\$132	\$132	\$66	\$66
	SUM (out-of-pocket)	\$1,934 (\$1,006)	\$2,076 (\$1,006)	\$486 (\$360)	\$484 (\$360)
Informal care	Care provided by family-caregiver	\$56,567	\$54,988	n. a.	n. a.
Productivity costs	Lost productivity of caregiver due to care responsibilities	n. a.	n. a.	\$556	\$556**
TOTAL		\$58,501	\$57,064	\$1,042	\$1,040

Key. PWD(s), person(s) with dementia.

* Costs based on diaries since no those costs were not collected using a questionnaire.

** Productivity costs were not measured at follow-up and therefore the baseline data were applied.

Note. All costs are shown in NZ \$.

Table 82 is an overview of the total annual cost per patient and per caregiver, but only based on those who actually utilised a service and for whom the costs occurred. It can be seen from these data that the annual costs are about one-third higher for patients and twice as high for caregivers compared to the average costs based on the entire sample. Again, costs were similar at baseline

and follow-up. It can also be seen that a smaller percentage of out-of-pocket expenses had to cover the total costs compared to means of the entire sample. Still, about 40% of patients' direct costs (not considering informal care) and about 55% of caregivers' direct costs were covered by participants themselves (out-of-pocket).

Table 82: Summary of mean annual costs per utilising PWDs and caregivers (questionnaire and diary data)

<i>Mean annual costs per utilising PWD/caregiver</i>		PWD		Caregiver	
		Baseline	Follow-up	Baseline	Follow-up
Medication	ChEIs	\$2,760	\$2,760	n. a.	n. a.
	Mental health*	\$17	\$17	\$0	\$0
Out-of-home-care	GP	\$348	\$348	\$348	\$348
	Specialist*	\$223	\$223	\$176	\$176
	Nurse*	\$21	\$21	\$50	\$50
Counselling	Psychologist and other*	\$0	\$0	\$23	\$23
In-home-care	Meals-on-wheels	\$93	\$93	n. a.	n. a.
Other out-of-pocket expenses	for example transportation*	\$157	\$157	\$113	\$113
	SUM (out-of-pocket)	\$3,619 (\$1,438)	\$3,619 (\$1,438)	\$710 (\$396)	\$710 (\$396)
Informal care	Care provided by family-caregiver	\$71,744	\$73,318	n. a.	n. a.
Productivity costs	Lost productivity of caregiver due to care responsibilities	n. a.	n. a.	\$1,404	\$1,404**
TOTAL		\$75,362	\$76,937	\$2,114	\$2,114

Key. PWD(s), person(s) with dementia.

*Costs based on diaries since no those costs were not collected using a questionnaire.

**Productivity costs were not measured at follow-up and therefore the baseline data were applied.

Note. All costs are shown in NZ \$.

In summary, costs were substantial no matter whether calculated based on means for the entire sample or only for those participants who utilised a certain service. The fact that the costs did not change significantly between baseline and follow-up is due these being average costs calculated using the same unit prices. Also, some costs were only assessed as out-of pocket expenses and the same mean costs were applied to baseline and follow-up calculations.

5.8.5 Perceived economic burden

The following results relate to the hypotheses as listed under points 1.a of chapter 3.3 (PWD's QoL may be predicted by caregivers' perceived economic burden), 1.b (caregivers' QoL is possibly influenced by their economic burden) and 3.d:

- Caregivers who are highly burdened consider that their financial situation is one of the most important determinants of their QoL.
- Caregivers of persons with moderate to severe dementia are at much higher risk of becoming depressed if they have low income.
- Caregivers' reactions to depressive and disruptive behaviours of PWDs may put them at risk of loss of economic resources.
- Family-caregivers of PWDs might want to be paid for their time spent caring.

An initial analysis of baseline data led to the concept of "perceived individual economic burden" as opposed to the societal economic burden. The subjective financial situation as perceived by patients (QOL-ADp item 12: "How do you feel about your financial situation?") and caregivers (QOL-ADc item 12) was significantly negatively correlated with caregivers' burden ($r = -.496, p < .001$; $r = -.271, p = .050$). The financial burden of care (BI item 15: "Do you feel you have enough money to care for your relative, in addition to the rest of your expenses?") was significantly associated with caregivers' QoL ($r = -.378, p = .005$), patients' QoL ($r = -.560, p < .001$), and with caregivers' burden ($r = .607, p < .001$) and distress scores ($r = .355, p = .009$). There was also a link between less subjective financial security (GDS item 23: "Do you think that most people are better off than you are? Yes/No") and a higher level of burden in caregivers ($r = .286, p = .038$). A closer investigation of participants by income groups revealed that caregivers with a lower income/pension were more depressed ($r = -.359, p = .008$) and had a significantly lower QoL ($r = .384, p = .005$) than caregivers with a higher income as is illustrated in **Figure 56**.

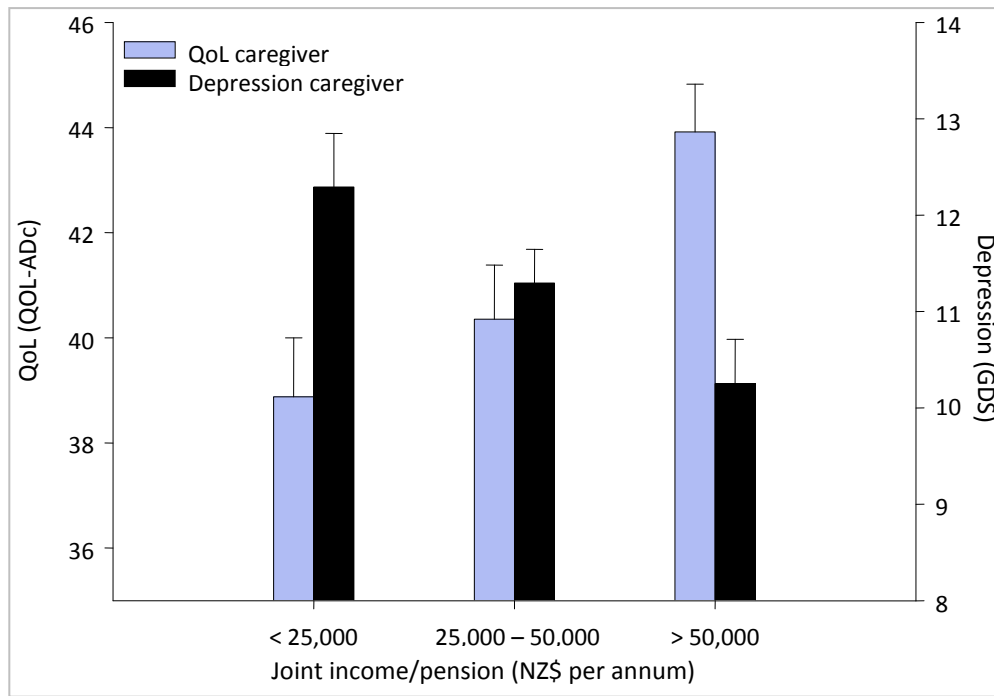


Figure 56: Correlation between participants' income/pension and caregivers' QoL and depression scores at baseline
 Key. QoL, Quality of life; QOL-ADc, Quality of Life-Alzheimer Disease Scale caregiver rating; GDS, Geriatric Depression Scale. Note. QoL: difference between income groups significant ($F_{2,50} = 4.64, p = .014$); Depression: difference between income groups significant ($F_{2,50} = 3.71, p = .032$).

A one-way ANOVA analysis showed that these findings were independent of participants' relationship (being daughter/son or spouse). This is important, since the assumption could have been made that participants in the lower income group might have been mainly spouses who would have been mostly retired and therefore had a lower income. The higher income group might have consisted mostly of daughters/sons or friends who would have been more likely to be employed. However, it was observed that the distribution of caregivers' QoL ratings (QOL-ADc) was statistically significantly different across the three income groups. In particular, QoL ratings were significantly better for the higher income group ($F_{2,50} = 4.64, p = .014$) and caregivers' depression levels (GDS) were significantly lower for the higher income group ($F_{2,50} = 3.71, p = .032$). Caregivers in the lower income groups also had a lower health status even though this difference did not reach statistical significance (Comorbidities c: $F_{2,50} = 2.55, p = .088$).

At follow-up, the fifth part of the Cost of Care Index (CCI) was included in the interview process providing a score on caregivers' burden related to economic costs. CCI data were collected from the sample of 33 caregivers who completed the follow-up assessment and 10 caregivers who

provided information after their relatives had moved into residential care. Three participants did not complete the CCI. The **table below** illustrates that one in four caregivers experienced moderate to severe economic burden and almost 50% of caregivers felt mildly burdened by their financial situation.

Table 83: Caregivers' perceived economic burden scores at follow-up

Severity of economic burden	CCI score	<i>n</i> (<i>n</i> = 40)	%
Minimal	4	12	30.0
Mild	5 – 8	18	45.0
Moderate	9 – 12	7	17.5
Severe	13 – 16	3	7.5

Based on the data collected during follow-up (*n* = 32) and using Pearson's correlation, it was found that the total CCI score (and in most cases all four CCI items) was correlated with the following QoL outcomes:

- PWDs' QoL: proxy ratings ($r = -.506, p = .003$),
- neuropsychiatric and behavioural symptoms ($r = .551, p = .001$),
- PWDs' health status: proxy ratings ($r = .511, p = .003$),
- caregivers' QoL ($r = -.450, p = .010$),
- caregivers' level of burden ($r = .543, p = .001$),
- caregivers' level of distress ($r = .663, p < .001$).

These results indicate that caregivers who felt more financially burdened at follow-up rated the QoL and health status of the PWDs lower and they were more likely to look after a PWD who had more (severe) neuropsychiatric and behavioural symptoms. If caregivers felt financially more strained, they also rated their own QoL lower and they were more burdened (BI) and distressed.

There were 17 out of the 43 caregivers who thought that financial assistance would help them/would have helped them to fulfil their role as caregivers and enable the PWDs to live at home for longer. This number translates into more than one-third (39.5%) of caregivers who would have liked to receive financial assistance so that they could take care of their relatives and friends with dementia at home for longer. No significant correlations were found between those who thought that financial assistance would help them to fulfil their role as caregivers for longer and any of the clinical QoL outcomes. However, these caregivers perceived their QoL as lower (QOL-ADc: $r = .297, p = .098$), and they felt their families could not afford little extras because of the expense to care for the PWD (CCI item 3: $r = -.335, p = .061$).

Based on these findings, the hypothesis that PWD's QoL may be predicted by caregivers' perceived economic burden was supported for caregivers' proxy ratings of PWDs' QoL but not for patients own QoL ratings. The hypothesis that caregivers' QoL is possibly influenced by their economic burden was also supported by the data.

The hypothesis that caregivers who are highly burdened consider that their financial situation is one of the most important determinants of their QoL could not be determined. At follow-up, there was not enough data to conduct a stepwise regression analysis which would have verified the predictors of QoL for caregivers who were highly burdened (BI score ≥ 41 : $n = 12$ out of 33). Therefore, it was not possible to establish if for those caregivers the financial burden (CCI score) was one of the most important factors. However, significant correlations were observed between the financial burden and both, caregivers' QoL and burden. Moreover, stepwise linear regression analysis for the entire follow-up sample showed that of all clinical outcomes caregivers' proxy ratings of patients' QoL (QOL-ADproxy) predicted caregivers' QoL the best (adj. $R^2 = .353, p = .001$). However, when controlling the analysis for the QOL-ADproxy ratings, it was shown that the CCI was the best predictor explaining 16.4% of variance (adj. $R^2 = .164, p = .019$). It can be concluded that caregivers' financial situation is perhaps not the most important predictor of caregivers' QoL but still an important factor.

Caregivers of persons with moderate to severe dementia are at much higher risk to become depressed if they have a low income. This hypothesis was supported for dementia in general. However, it does not follow that only lower income caregivers of persons with moderate to severe dementia are more likely to become depressed. A two-way ANOVA showed that the differences in caregivers' depression levels (GDS) between income groups were independent of patients' stage of dementia (CDR).

The correlations found between caregivers' distress scores and all CCI items supported the hypothesis that caregivers' reactions to depressive and disruptive behaviours of PWDs may put them at risk of loss of economic resources.

The hypothesis was also supported that family-caregivers of PWDs might want to be paid for their time spent caring.

5.9 Summary of results

The following is a summary of all findings relating to PWDs' and caregivers' QoL predictors, the formal care utilisation of this study population and the economic outcomes. Each section starts with those outcomes that were expected and which did support the hypotheses, followed by those outcomes that were unexpected and which did not support the hypotheses.

5.9.1 Clinical predictors of patients' quality of life

All outcomes supported the hypotheses related to patients' QoL.

5.9.1.1 *Expected predictors of patients' quality of life*

- Pathology of dementia (AD predicting better QoL than VD or mixed dementia)
- Dementia severity (better QoL at an earlier stage of dementia)
- PWDs' level of depression
- Prevalence of neuropsychiatric and behavioural symptoms
- Level of impairment of PWDs' daily functioning
- PWDs' general health or comorbidities prevalent in addition to the dementia
- Caregivers' QoL
- Caregivers' burden
- Caregivers' level of distress (predicting carers' proxy ratings of PWDs' QoL and predicting PWDs' ratings of their own QoL)
- Caregivers' perceived economic burden (CCI)
- Similar QoL predictors were observed over time (12 months) but some clinical values deteriorated during that time (severity of dementia, cognition, neuropsychiatric and behavioural symptoms, daily functioning).

5.9.1.2 Expected factors not predicting patients' quality of life

- Level of cognitive impairment
- Caregivers' level of depression
- Support caregivers receive from family and friends (only supported for QOL-ADproxy)
- Caregivers' health
- Caregivers' perceived economic burden

5.9.2 Clinical predictors of caregivers' quality of life

The factors which impacted on caregivers' QoL differed considerably from the ones which had been expected. Interestingly, it was found that patients' neuropsychiatric and behavioural symptoms and caregivers' level of depression, which were both predictors of QoL in the level-1 studies, did not predict caregivers' QoL in this study. Also, unlike other studies, patients' impairment in daily functioning did impact on caregivers' QoL in this study.

5.9.2.1 Expected predictors of caregivers' quality of life

- Dementia severity (better QoL at an earlier stage of dementia)
- PWDs' QoL
- PWDs' health (patient perspective)
- Caregivers' burden
- Caregivers' level of distress (only approached statistical significance)
- Caregivers' perceived support from family and friends
- Caregivers' health
- Economic burden (income and CCI)
- Similar QoL predictors were observed over time (12 months).
- Coping abilities and process varied during 12 months.

5.9.2.2 Expected factor not predicting caregivers' quality of life

- PWDs' level of depression

5.9.2.3 Unexpected predictor of caregivers' quality of life

- PWDs' level of impairment of daily functioning

5.9.2.4 Unexpected factors not predicting caregivers' quality of life

- Caregivers' gender (being female)
- Pathology of dementia
- PWDs' cognition
- PWDs' neuropsychiatric and behavioural symptoms
- PWDs' health (caregiver perspective)
- Caregivers' level of depression

5.9.3 Formal interventions in New Zealand (Canterbury)

Hypotheses relating to formal care outcomes were based on a few level-1 studies and some level-2 studies, none of which had been conducted in New Zealand. It is therefore not surprising that many hypotheses were either not supported by the data of this study or could not be determined.

5.9.3.1 Expected formal care outcomes for patients

- Taking advantage of available support options resulted in fewer negative changes regarding patients' QoL.
- Combined information and support interventions achieved significantly better patient QoL than single interventions. Best outcomes were found for PWDs who utilised a combination of two interventions.

5.9.3.2 Unexpected formal care outcomes for patients

- Cholinesterase inhibitors (ChEIs) did not seem to have a positive impact on patients' cognitive and daily functioning, particularly in mild to moderate dementia.
- The utilisation of medical interventions did not seem to improve PWDs' QoL over time.
- The utilisation of social supports and interventions did not seem to improve PWDs' QoL over time (day care, sitter service and support groups).
- The utilisation of psychological supports and interventions did not seem to improve PWDs' QoL during the 12 months.

5.9.3.3 Formal care outcomes for patients which could not be determined

- It could not be determined whether early diagnosis resulted in decreased patients' neuropsychiatric and behavioural symptoms.
- It could not be determined whether the utilisation of educational supports and interventions improved PWDs' QoL over time.
- It could not be determined whether the utilisation of educational supports and interventions positively impacted on PWDs' neuropsychiatric and behavioural symptoms and QoL.
- It could not be determined whether non-pharmacological interventions were most effective when they are not only directed at the PWD but also at the caregiver since none of the formal interventions available in Canterbury is specifically designed to be directed at both.

5.9.3.4 Expected formal care outcomes for caregivers

- Higher levels of caregiver stress seemed to cause an increase in the use of medical services (utilisation of mental health medication: caregivers and PWDs, hospitalisation: PWDs, utilisation and number of doctor contacts: PWDs).
- Combined information and support interventions achieved better caregiver QoL than single interventions (tendency). Caregivers who utilised seminars, support groups and counselling had the best QoL and also felt the most supported by family and friends.

5.9.3.5 Unexpected formal care outcomes for caregivers

- The utilisation of most types of medical interventions did not improve caregivers' QoL over time.
- Seminars offered by Alzheimers Canterbury did not seem to improve caregivers' depression, burden or reactivity to difficult behaviours.
- The utilisation of educational supports and interventions did not seem to improve caregivers' QoL over time.
- The utilisation of social supports and interventions did not seem to improve caregivers' QoL over time (day care, sitter service and support groups).
- The utilisation of psychological supports and interventions did not seem to improve caregivers' QoL during the 12 months.

5.9.3.6 Formal care outcome for caregivers which could not be determined

- It could not be determined whether non-pharmacological interventions were most effective when not only directed at the PWD but also at the caregiver.

5.9.4 Economic analysis

Hypotheses relating to the economic evaluation were based entirely on level-2 studies none of which had been conducted in New Zealand. However, the majority of hypotheses were indeed supported by the data of this study. Only some predicted outcomes were either not supported by the data or could not be determined.

5.9.4.1 *Expected economic outcomes for patients*

- Direct medical costs did increase with increasing dementia severity, increasing behavioural symptoms and increasing functional limitations.
- Direct non-medical costs, not including costs of informal caregiving time, did increase with increasing dementia severity, increasing behavioural symptoms as well as increasing functional limitations.
- Costs did increase more with the severity of patients' functional disability than with patients' cognitive impairment.
- PWD's QoL was predicted by caregivers' perceived economic burden (only caregivers' proxy ratings of PWDs' QoL).

5.9.4.2 *Unexpected economic outcome for patients*

- Direct non-medical costs of PWDs living at home, not including costs of informal caregiving time, did not increase with the severity of patients' cognitive impairment.

5.9.4.3 *Economic outcome for patients which could not be determined*

- It could not be determined whether direct medical costs of PWDs living at home did increase with the severity of patients' cognitive impairment.

5.9.4.4 *Expected economic outcomes for caregivers*

- The costs of informal caregiving hours (like other costs) increased with increasing dementia severity, increasing behavioural symptoms as well as increasing functional limitations.

- Caregiving hours did have a significant negative impact on caregivers' psychological health.
- Caregivers' QoL was influenced by their economic burden.
- Caregivers were much more likely to be depressed if they had a low income.
- Caregivers' reactions to depressive and disruptive behaviours of PWDs might have put them at risk for loss of economic resources.
- Some family-caregivers (39.5%) wanted to be paid for their time spent caring for the PWD.

5.9.4.5 Unexpected economic outcomes for caregivers

- Caregiving hours did not seem to have a significant negative impact on caregivers' physical health.
- Indirect costs (here: productivity costs) did not increase with increasing dementia severity and behavioural symptoms, or with decreasing functional and cognitive abilities.

5.9.4.6 Economic outcome for caregivers which could not be determined

- It could not be determined if caregivers who were highly burdened considered that their financial situation is one of the most important determinants of their QoL.

6 Discussion

This chapter is a discussion of the study's findings. Special interest is paid to those outcomes which were unexpected and possible explanations are proposed. Predictors of PWDs' and caregivers' QoL are discussed first (p. 320), followed by formal interventions and their utilisation and impact on QoL (p. 332). Finally, the costs covered by PWDs and their caregivers (p. 339) as well as strengths and limitations of this study (p. 345) are considered. This chapter starts with an overview of how the QoL predictors from this study compare to findings from studies included in the systematic literature review of chapter 2.

6.1 Study's findings vs. results of the literature review

As outlined at the end of the previous chapter, most clinical results from this study were similar or even the same as findings from other studies³⁸.

All outcomes supported the hypotheses related to patients' QoL. However, unlike some of the reviewed studies, it was found that patients' own QoL ratings were better predicted by their functional impairment than were caregivers' proxy ratings at baseline. Also, functional impairment was already a strong predictor at baseline when the majority of patients had early dementia. Taking all clinical outcomes together, the impairment of patients' IADLs was a better predictor of their QoL than the ADL limitations.

A number of differences were observed between caregiver QoL outcomes in other studies and this study's findings. Patients' neuropsychiatric and behavioural symptoms and caregivers' level of depression did not predict caregivers' QoL in this study. Also, patients' impairment in daily functioning did impact on caregivers' QoL in this study. However, some of the hypotheses regarding caregiver outcomes were not based on the literature review which had included only two level-1 studies. Those two studies did not measure or report all outcomes of interest to the

³⁸ Comparison only with studies included as level-1 or level-2 studies in the systematic review of literature (chapter 2)

researcher. The caregiver findings were therefore more difficult to compare with outcomes from the literature review and they were also more likely to differ from these two studies (**Table 84**).

Table 84: Results compared to findings from level-1 studies

	Factor	QoL predictor in this study	QoL predictor in level-1 studies	Comparison
QoL PWD	Pathology	Yes	Not measured/ reported	n.a.
	Severity	Yes (QoL p and proxy)	Yes: QoL proxy (1 study)	Similar
	Cognition	No	Mostly no If yes: QoL proxy more often than QoL p	Similar
	Depression PWD	Yes	Inconclusive: stronger predictor if all stages of dementia	Similar
	NPI	Yes	Yes	Same
	ADL/IADL	Yes; stronger for p than proxy; strong for mild to moderate; better for IADL than ADL	Yes, but stronger for QoL proxy than p; less strong for mild to moderate dementia	Somewhat different
	Health PWD	Yes: comorbidities proxy	Yes: physical health; Yes: pain	Same
	QoL carer	Yes	QoL p (only money item) correlated with QoL c (only money item) (only 1 study); QoL proxy correlated with QoL c (1 study)	Similar
	Burden carer	Yes	Yes (1 study)	Same
	Distress carer	Yes (QoL p and proxy)	Yes: QoL p (3 out of 4 studies); Yes: QoL proxy	Same
	Depression carer	No	No (1 study)	Same
	Informal support for carer	Yes Significant: QoL proxy Tendency: QoL p	Not measured/ reported	n. a.
	Health carer	Yes Not correlated but linked with stepwise regression analysis.	Yes: mental health (GHQ-12) correlated with QoL proxy (1 study)	n. a.
	Economic burden carer	Yes	Not measured/ reported	n. a.
	Gender PWD	No	No (1 study)	Same
	Age PWD	No	Inconclusive: Yes (3 studies): increasing age – better QoL proxy No (2 studies); often not reported	n. a.
	Gender carer	No	Not measured/ reported	n. a.
	Age carer	No	No (1 study)	Same
	Spouse or parent	No	Not measured/ reported	
	Joint income	No	Not measured/ reported	n. a.
QoL Carer	QoL PWD	Yes	Inconclusive: Yes (1 study): proxy rated No (1 study): self rated and proxy rated	n. a.
	Pathology	No	Yes (1 study): carer QoL lower for cares of persons with LBD as compared to AD	n. a.
	Severity	Yes	Not measured/ reported	n. a.
	Cognition	No	Not measured/ reported	n. a.
	Depression PWD	No	No (1 study)	Same
	NPI	No (only yes for disinhibition)	Yes (2 studies)	Different
	ADL/IADL	Yes (total BADLS and after split into ADL and IADL: IADL)	No (1 study)	Different
	Health PWD	Yes: comorbidities p	Not measured/ reported	n. a.
	Burden carer	Yes	Not measured/ reported	n. a.
	Distress carer	Yes (but only approached statistical significance)	Yes (1 study)	Similar
	Depression carer	No	Yes (1 study)	Different
	Informal support for carer	Yes	Not measured/ reported	n. a.
	Health carer	Yes	Not measured/ reported	n. a.
	Economic burden carer	Only tendency	Not measured/ reported	n. a.
	Gender PWD	No	Not measured/ reported	n. a.
	Age PWD	No	Not measured/ reported	n. a.
	Gender carer	No	Yes (1 study): QoL lower for women	Different
	Age carer	No	Not measured/ reported	n. a.
	Spouse or child	No	Not measured/ reported	n. a.
	Joint income	Yes	Not measured/ reported	n. a.

6.2 Predictors of patients' quality of life

6.2.1 Socio-demographic factors

PWDs' age was negatively correlated with their depression levels and caregivers' distress and depression scores indicating that younger PWDs were more likely to develop depressive symptoms or become depressed and their caregivers were more distressed and also more depressed. A study conducted by Covinsky, et al. (2003) also found that caregiver depression was predicted by younger patient age. In the same study population, Sink, Covinsky, Barnes, Newcomer, & Yaffe (2006) established furthermore that "caregivers who were younger, less educated and more burdened" or spent more hours caregiving reported more neuropsychiatric symptoms in persons with dementia living in the community than other caregivers.

Additionally, in this study it was not found that older patients received better QoL ratings from their caregivers. This result differs from findings of three level-1 studies conducted in patients with mild to moderate dementia which had all found a link between increasing patient age and better patient QoL (Banerjee, et al., 2006; Matsui, et al., 2006; Ready, et al., 2004). Banerjee, et al. (2006) concluded that "older patients and their carers may find it easier to adapt to dementia" and speculated that "they have had more experience of dementia in their peers, because they are free of the expectations of the early retirement, or perhaps because their peers are more accepting of dementia". Based on the current findings, it can be hypothesised that in New Zealand (Canterbury) increasing patient age is not a predictor for better proxy ratings of their QoL but it is a predictor for better depression (patient and caregiver) and distress (caregiver) outcomes. Banerjee, et al.'s (2006) speculation for the link between age and QoL can easily be applied to the link between age and depression/distress. However, it has to be considered that it is difficult to compare this study's age-related findings with other research (level-1 articles) since it is often not explicitly reported whether or not age was linked with patients' or caregivers' QoL.

The researcher found that in this study women with dementia were likely to be looked after by children or by a brother or sister whereas men with dementia were likely to be looked after by their spouses. The reason might be that, as confirmed by the data, women with dementia were older than men, which means that their spouses might have died. Men with dementia, on the other hand, were younger and therefore possibly more likely to be looked after by their spouses. However, one-way ANOVA showed no significant differences between married men with dementia and other men with dementia in this cohort ($F_{2,28} = 0.81, p = .456$). There was also no significant difference between married women with dementia and other women with dementia in this study ($F_{2,18} = 0.44, p = .649$). The sample size was possibly too small to detect any group differences and the explanation for the patient caregiver relationship status remains speculative.

6.2.2 Pathology

The pathology (type of dementia) was hypothesised to be a predictor of QoL, despite the fact that none of the level-1 or level-2 articles had identified this factor to impact on PWDs' QoL. In this study, the type of dementia was strongly related to a number of outcomes. For example, PWDs' QoL was rated higher by both, PWDs and caregivers if they had been diagnosed with AD as compared to VD and mixed dementia. This might be explained by the fact that participants with VD or mixed dementia had more neuropsychiatric and behavioural symptoms as well as higher depression rates and were further advanced in their illness as compared to participants with AD. It can be concluded, therefore, that persons with VD or mixed dementia experienced lower QoL overall.

6.2.3 Daily functioning

Unlike some of the reviewed studies (Edelman, et al., 2004; Logsdon, et al., 2002; Ready, et al., 2004; Snow, et al., 2005), it was found that at baseline patients' functional impairment was a slightly stronger predictor for their own QoL ratings than for caregivers' proxy ratings. Then again, at follow-up, caregivers' proxy-ratings were stronger correlated with patients' level of functional

impairment ($r = -.651, p < .001$) than patients' own QoL ratings which only approached statistical significance ($r = -.344, p < .058$). Also, functional impairment was already a strong predictor at baseline when the majority of patients had early dementia. This result differs from those level-1 studies which found hardly any association between patient QoL and functional impairment in samples of mild to moderate dementia (Fuh & Wang, 2006; Matsui, et al., 2006).

Moreover, the data from this study indicated that the level of IADL impairment was a better predictor of PWDs' and caregivers' QoL than the level of ADL limitation, at least at an earlier stage of dementia. These results seem to support a more comprehensive approach to QoL than the one suggested by the concept of HRQoL.

6.2.4 Patient vs. proxy ratings

As described in section 1.2.2 of the introduction chapter (p. 22), researchers debate the advantages and disadvantages of patients' self-reported QoL vs. caregivers' proxy ratings of patients' QoL. Bearing in mind that caregivers' proxy-ratings of PWDs' QoL are influenced by their own QoL (Fuh & Wang, 2006; Ready, et al., 2004; Vogel, et al., 2006), it has been argued that "proxy-ratings can be considered as complementary information for self-ratings but not as a substitute" (Riepe, et al., 2009).

Similarly, the author of this current study suggested earlier (chapter 1, p. 22) that "... PWDs' QoL is best assessed by obtaining both PWDs' self-ratings as well as caregivers' proxy-ratings". Comparable to all nine level-1 studies who have assessed patients' QoL using both self and proxy ratings (Edelman, et al., 2004; Fuh & Wang, 2006; Hurt, et al., 2008; Logsdon, et al., 2002; Matsui, et al., 2006; Ready, et al., 2004; Shin, et al., 2005; Snow, et al., 2005; Vogel, et al., 2006), the researcher also found that patient ratings of their own QoL were on average higher than caregivers' proxy ratings. Furthermore, caregivers rated patients' QoL lower than patients themselves across all stages of dementia. However, none of these differences were statistically significant. Only the difference between patient and proxy ratings for those patients who had a

CDR of 1 at baseline approached statistical significance ($F_{17,15} = 2.29, p = .057$). The correlation between self and proxy ratings of patient QoL at baseline ($r = .688, p < .001$) and follow-up ($r = .466, p = .008$) indicates a modest level of agreement between both outcomes. Similar to patients' QoL, caregivers also rated patients' health status lower than patients themselves. Pearson's correlation revealed that both proxy ratings of patients' QoL and of patients' health were predicted by a number of factors including the following (which applied to both proxy outcomes):

- stage of illness,
- PWDs' QoL: patient ratings,
- level of daily functioning,
- caregivers' level of burden.

Linear regression analysis showed that caregiver's proxy ratings of patients' QoL were best predicted by patients' and caregivers' own QoL and carers' burden. When the researcher controlled for all caregiver outcomes, it was found that, in addition to patients' QOL-AD ratings, patients' neuropsychiatric and behavioural symptoms also strongly predicted how caregivers would evaluate PWDs' QoL. Both variables together explained 51.0% of the variance of QOL-AD proxy scores. Earlier studies also found that the discrepancy between self and proxy rated patient QoL was predicted best by patients' level of functional impairment (Edelman, et al., 2004; Snow, et al., 2005), by neuropsychiatric and behavioural symptoms (Hurt, et al., 2008; Ready, et al., 2004; Shin, et al., 2005), by caregivers' level of depression (Logsdon, et al., 2002; Ready, et al., 2004; Snow, et al., 2005) and by caregivers' perceived burden (Logsdon, et al., 2002).

There are several possible explanations for this discrepancy between self and proxy ratings. First, patients' cognitive impairments might result in reduced insightfulness. However, even though Vogel, et al. (2006) found that in patients with mild AD the lack of insight into their symptoms was associated with the differences in self and proxy ratings, Ready, et al. (2004) had opposing results. Logsdon, et al. (2002) also argued that cognition was not the most prominent explanatory factor.

This argument was supported by the data of this current study. Another explanation for differences in patient and caregiver ratings of patients' QoL might be the impact of caregiver outcomes such as depression, distress and burden. Caregivers' own experience of the patient's illness might influence how they perceive the patient's QoL, which is supported by this study's data. This explanation fits very closely with a systemic approach to QoL in dementia where patients and caregivers are seen as individual systems. These systems have points where their experiences, perceptions and interpretations of their environments overlap but in no way are a complete match. Finally, it has been argued by Ready, et al. (2004) that elderly patients who experience loss of cognitive abilities may cope by emphasising other life domains. In this concept, cognitive impairment becomes less important and its impact on PWDs' QoL decreases.

6.3 Predictors of caregivers' quality of life

6.3.1 Socio-demographic factors

It was unexpected to find that the QoL of women who looked after PWDs was not lower than the QoL of men taking care of a PWD since one of the two level-1 studies which considered caregivers' QoL (Thomas, et al., 2006) had found that caregiver QoL was significantly lower for women than for men. Similar to the current study, Thomas, et al. (2006) had included persons with different dementias and their informal caregivers. Also similarly, there were more women who provided care than men with women being significantly younger than men. However, in Thomas, et al.'s (2006) study, there were 84% of patients who had been diagnosed with AD compared to 59% in this current study. Thomas, et al. (2006) compared their findings with Thompson, et al. (2004), who had also found that female spousal caregivers had significantly worse QoL outcomes than male caregivers including stress, depression and burden. But it has to be taken into consideration that Thompson, et al. had conducted their study in a sample of only AD patients and their spousal caregivers and that the authors had not measured caregivers' QoL *per se*. In conclusion, it might be that this study did not enrol enough participants to detect differences in caregivers depending

on their gender or that such differences are more prominent in cohorts of caregivers' of persons with AD than vascular or mixed dementia.

6.3.2 Pathology

In this study, caregivers' QoL was not predicted by the type of dementia. However, the hypothesis was based on a study which found that caregivers' QoL was lower when they looked after a person with Lewy Body Dementia (LBD) as compared to AD (Thomas, et al., 2006). It could be argued that this finding should not have been generalised and hypothesised for other dementias. Since none of the participants of this study had been diagnosed with LBD, the result that no differences in caregivers were found depending on whether they looked after somebody with AD, VD or mixed dementia is not completely unexpected.

6.3.3 Patients' level of cognitive impairment

It was somewhat unexpected to find that caregivers' QoL was not predicted by patients' level of cognitive impairment. However, neither Shin, et al. (2005) nor Thomas, et al. (2006), the two caregiver level-1 studies, found that patients' cognition was linked to caregivers' QoL. The author of this study nevertheless hypothesised such a correlation, in an effort to take as comprehensive an approach to identify potential QoL predictors as possible. The fact that this study confirms both Shin, et al.'s (2005) as well as Thomas, et al.'s (2006) earlier findings shows that the severity of cognitive impairment in persons with dementia seems to have little or no influence on informal caregivers across different dementias and different stages of illness.

6.3.4 Patients' neuropsychiatric and behavioural symptoms

One of the most striking and unexpected results was that caregivers' QoL was not predicted by patients' neuropsychiatric and behavioural symptoms. Both level-1 studies had established the negative impact of these symptoms on caregivers' QoL. Using the same instruments (NPI and QOL-AD) in a cohort of persons with mild to moderate AD, Shin, et al. (2005) found negative correlations between caregivers' QoL ratings and the total NPI score ($r = -.369, p < .01$) as well as

four of the NPI domains: agitation/aggression, anxiety, disinhibition and irritability/lability. Thomas, et al. (2006) only reported the total NPI which the authors found to be significantly related to caregivers' QoL ($\rho = -.486, p = .003$). Similar to the result that caregivers' gender was not a predictor of their QoL in this study there are a couple of possible explanations for this outcome. Again, it might be that this study did not enrol enough participants to detect differences in caregivers' QoL depending on the prevalence and severity of patients' neuropsychiatric and behavioural symptoms or that such differences are more prominent in cohorts of caregivers' of persons with AD than vascular or mixed dementia. Furthermore, the symptoms themselves might be less significant in terms of their ability to predict caregivers' QoL than caregivers' reaction to these symptoms since the correlation between caregivers' QoL and distress scores (NPI-D) approached statistical significance.

6.3.5 Patients' level of impairment of daily functioning

Surprisingly, in this study, caregivers' QoL was predicted by the severity of patients' level of functional impairment. This result is contradictory to the findings of the study conducted by Thomas, et al. (2006) where, using a stepwise regression analysis, patients' functional impairment was not significantly related to caregivers' QoL. It is possible that the difference in outcomes between both studies is due to methodological differences. Thomas, et al. (2006) had used Katz' Activities of Daily Living Scale whereas the current study used the Bristol Activities of Daily Living Scale for assessment of patients' level of daily functioning. Katz's scale consists of six items regarding only limitations of basic ADLs while the BADLS incorporates 20 items covering both basic activities of daily living (ADLs) and more complex instrumental activities of daily living (IADLs). The argument that those different scales might be the reason for different outcomes is supported by another finding of this current study whereby patients' level of impairment of IADLs was a better predictor of patients' QoL than their impairment of ADLs. As reported earlier (p. 219), the correlation found between patients' total BADLS scores and caregivers' QOL-ADc ratings was statistically significant but not very strong ($r = -.284, p = .039$). After splitting the total BADLS

scores, it was found that only patients' IADL scores but not ADL ratings were significantly correlated with caregivers' QoL scores ($r = -.292, p = .034$). It also has to be considered, that these correlations were not found to be statistically significant at follow-up, which could be due to smaller numbers of participants for whom follow-up data could be collected. It is also possible that functional impairment becomes a less prominent predictor of caregivers' QoL over time with other factors related to their own coping ability becoming increasingly important. However, decreasing ADLs and IADLs were emerging from the qualitative data as one group of factors which impacted negatively on caregivers' coping during the year between assessments.

Taken together, these findings suggest that at an early stage dementia, it is not patients' general level of functioning which predicts caregivers' QoL, but patients' limitations regarding the more complex IADLs. This distinction also applies to a certain degree to patients' QoL.

6.3.6 Patients' health status

Another unanticipated finding was that caregivers' QoL was predicted by patients' health status or comorbidities but only from patients' own perspective and not from caregivers' perspective (Comorbidities proxy). No level 1-study measured or reported such a relationship but it was expected that caregivers' QoL is possibly influenced by PWDs' health status and the above finding shows that this hypothesis was supported. However, it was still unexpected that caregivers' perception of patients' health (Comorbidities proxy-ratings) was not linked to caregivers' own QoL ratings. This finding also seems to contradict the qualitative data collected at follow-up. Similar to patients' functional impairment, patients' health status was emerging as one factor which negatively impacted on caregivers' coping during the year between assessments. Nevertheless, it could also be argued that caregivers' QoL was indeed lower for those who looked after patients with a worse health status but caregivers' lower QoL did in return not impact on how they rated patients' health status.

6.3.7 Caregiver depression

Contrary to expectations based on the systematic review of literature, this study did not find a significant correlation between caregivers' level of depression and their QoL. This was unexpected since Thomas, et al. (2006) had found a highly significant relationship between both outcomes ($p = .001$). However, Thomas, et al. (2006) utilised the mini-GDS (Clement, Peugnet, Preux, & Leger, 2000) to assess depression in caregivers. This instrument consists of only one question: "Are you depressed?" which distinguishes it clearly from the GDS used in this current study which consisted of 30 items.

Another methodological aspect might also explain the differences in outcomes between both studies. As outlined in the methodology chapter (p. 141), the GDS was originally developed for use with older persons and not, as in this study, for caregivers of all ages. However, after splitting caregivers in two groups depending on their age (< 65 years or ≥ 65 years of age), one-way ANOVA showed no significant group differences regarding caregivers' depression rates at baseline. This outcome does not support the hypothesis that the missing relationship in this study between caregivers' depression levels and their QoL was due to the methodological issue of applying a scale to different age groups than intended by the scale developers.

Therefore, a different approach to analysing the data was taken. Instead of detecting group differences using one-way ANOVA, Pearson's correlation was applied. A significant negative relationship between the factor 'being < 65 years of age' (true: 1, false: 2) and caregivers' depression scores was observed ($r = -.420$, $p = .019$). This suggests that caregivers who were younger than 65 years of age had significantly higher depression rates at baseline than older caregivers. Again, the methodological approach to assess caregivers' depression scores did not seem to explain the differences in outcomes between this study and the one conducted by Thomas, et al. (2006).

Regardless, this finding is still of interest and consistent with an earlier outcome presented in the previous chapter where it was observed that caregivers were more likely to be depressed if they looked after younger PWDs. Younger PWDs might have been more likely to be looked after by siblings or spouses who were also younger, but no statistically significant differences were found to support this hypothesis. In conclusion, even though caregivers' depression levels were no significant predictor of their QoL *per se* in this study, depression was still an important clinical outcome that should be assessed, especially in younger caregivers and those who look after younger PWDs.

There were also indications that caregivers were more likely to be depressed if they looked after a less cognitively impaired PWD. This seems surprising at first, since it could have been expected that caregivers' could be more likely to be depressed the more cognitively and therefore also functionally impaired the person is they look after (baseline correlation between cognition and functioning: $r = -.328$, $p = .018$; follow-up: $r = -.491$, $p = .004$). However, it might be that less cognitive impairment is an indicator for participants having been diagnosed with dementia at a younger age. This was not supported by the data but it has to be considered that only 2 PWDs were younger than 65 years of age in this current study.

In addition to lower patient age as a possible explanation for increased depression rates in caregivers, there is also the concept of insightfulness. Less cognitively impaired PWDs have more insight into their illness (Zanetti, et al., 1999) and an increased awareness for their loss of independence (Harwood, Sultzer, & Wheatley, 2000) which might in turn make it more difficult for their caregivers to cope possibly resulting in higher depression rates. Interestingly, in a recent study it was found that impairment of insight was associated with better HRQoL in persons with moderate AD but cognition - not insight - was related with decreased HRQoL in participants with mild dementia (Hurt, et al., 2009). According to the authors, impaired insight might be a protective factor for PWDs. Similarly, Draper, Peisah, Snowden, & Brodaty (2010) recently argued that

minimisation and denial could be interpreted as either “emotion-focused coping strategies or as an intrinsic part of the disease biology”, but that in either case they were protective mechanisms with regards to the illness impact.

6.3.8 Caregivers’ health status

The data of this current study suggested that caregivers’ health status together with their perception of patients’ QoL predicted 60% of the variance of caregivers’ total QoL scores. Interestingly, when asked what the primary reasons for patients’ admittance into permanent care were, none of the 10 caregivers’ perceived their own poor health as the trigger. These outcomes are so contradictory that only a few possible explanations seem reasonable. Firstly, the data might be wrong. If this is the case, it seems more likely that the data regarding the permanent care reasons rather than the data regarding caregivers’ QoL predictors might be faulty, since caregivers’ could be reluctant to admit that it was their own health which played an important role in their decision. Underlying this might be the aspect of denial as a coping mechanism. This is somewhat supported by the finding that patients’ worsening cognition was the number one reason for permanent care. Cognition was chosen by more caregivers (70%) than any other offered choice even though cognition was neither a predictor of patients’ nor of caregivers’ QoL throughout the study.

Secondly, the outcomes regarding causes for admission into permanent care could have been very different if data from a bigger study population were available. Data obtained from 10 participants does not have enough statistical power from which to draw irrefutable conclusions.

Finally, the above findings might not be as contradictory as they seem at first. Caregivers’ QoL is influenced by their health without necessarily leading to the conclusion that caregivers’ health (or QoL) must therefore also be a predictor for patients’ change into permanent care. This would, however, imply that caregivers’ see their QoL very separate from patients’ QoL. The data of this study suggests otherwise with an emphasis on the close unit of PWD and caregiver.

6.4 Change over time

Similar predictors of patient and caregiver QoL were observed over 12 months. None of the caregiver outcomes changed significantly. However, the stage of dementia, patients' cognition, level of daily functioning, as well as neuropsychiatric and behavioural symptoms all significantly deteriorated within 12 months. It could either be interpreted that 1 year might be not enough time to observe significant changes in factors that influence especially caregivers' quality of life or that it is possible to sustain QoL in dementia for 1 year. This finding supports earlier research where the authors found no mean change in QoL over 12 months in a mixed sample of PWDs aged 65 years or over (Selwood, Thorgrimsen, & Orrell, 2005). The authors concluded that PWDs did not perceive that their QoL declined over 12 months.

Interestingly, Pearson's correlation analysis showed that a number of significant baseline correlations between patients' self rated QoL and other clinical QoL outcomes were not maintained at follow-up: NPI total score, BADLS, QOL-ADc, BI and NPI-D. These correlations were, however, maintained for caregivers' proxy ratings of PWDs' QoL. These findings support the theory that patients' ability to rate their own QoL might decrease with progressing dementia, as discussed above (6.2.4, p. 322).

A number of conclusions regarding predictors of QoL in dementia can be drawn from this study's findings:

1. Quality of life in dementia is predicted by a variety of clinical and non-clinical factors.
2. Depression in patients and caregivers, each other's QoL, patients' neuropsychological behaviours and functioning, as well as caregivers' burden, and the level of informal care can predict QoL in dementia.
3. Similar predictors of patient and caregiver QoL can be observed over 12 months.

4. Quality of life of persons with dementia and their caregivers is closely linked. It is necessary to assess both.
5. Quality of life of persons with dementia does not simply decrease with decreasing cognition but with illness progression.
6. However, the degree of cognitive impairment is an important predictor for the level of formal care needed.

6.5 Formal supports/interventions

6.5.1 Early diagnosis

It could not be determined whether early diagnosis resulted in decreased patients' neuropsychiatric and behavioural symptoms. However, neuropsychiatric and behavioural symptoms in patients with early diagnosis increased less, by almost 50%. This finding is consistent with the outcomes of Banerjee, et al. (2007) who evaluated the Croydon Memory Service Model. The focus of this service model is early diagnosis and support for PWDs and their caregivers. In the service evaluation study, the majority (68.0%) of referrals had minimal to mild dementia which is comparable with this study's 83.0%. Banerjee, et al. (2007) found that patients' mean total NPI score had decreased statistically significantly at 6-month follow-up.

6.5.2 Medical and domestic supports/interventions

6.5.2.1 Medication

ChEIs did not seem to have a positive impact on patients' cognitive and daily functioning, particularly in mild to moderate dementia. However, there were indications that ChEIs/Memantine might have a positive impact on patients' neuropsychiatric and behavioural symptoms. On the other hand, it appears that PWDs who showed increased psychosis symptoms (hallucinations and delusions) were more likely to utilise dementia medication already at baseline which seemed to have a positive effect on those symptoms in particular. This finding suggests that

the observed positive impact of dementia medication on patients' neuropsychiatric and behavioural symptoms might be due to the fact that patients with psychosis symptoms were more likely to be prescribed those medications. An improvement of those symptoms is therefore not unexpected.

6.5.2.2 Professional out-of-home and in-home care

The utilisation of medical and domestic interventions did not seem to improve PWDs' QoL over time. However, patients who had a nurse supporting them in their homes had significantly higher QoL ratings compared to those who did not utilise this service and whose QoL remained the same over the 12-months period.

The utilisation of most types of medical interventions did not improve caregivers' QoL over time. However, caregivers felt less burdened if the PWD had been hospitalised during the year which would support the hypothesis. On the other hand, caregivers also felt less supported if they themselves had been hospitalised. And even though the data from this study supported the hypothesis that higher levels of caregiver stress are associated with an increase in the use of medical services (such as patients' doctor contacts and hospitalisation), it seems more likely that distress was a result rather than a cause. This theory is supported by the finding that caregivers were more distressed if patients received less in-home support (domestic and personal care needs). Again, distress seems to be the result rather than the cause, but this outcome points towards in-home support as an important intervention not only regarding patients' QoL but also caregivers' QoL outcomes.

PWDs with more impaired cognition received more and longer³⁹ in-home care contacts in the 2 weeks prior to baseline and follow-up assessments. This is not an unexpected outcome, since it was predicted that medical (and non-medical costs) would increase with PWDs' increasing

³⁹ Longer contacts only statistically significant at follow-up.

cognitive impairment which implies the above outcome. However, considering the significant impact of overall illness progression on patients' and caregivers' QoL as well as on costs, the question arises, "is formal care allocation in Canterbury currently focussing too much on patients' level of cognitive impairment?" In the future it might be necessary to review the current service allocation model and refocus it on a comprehensive approach where the overall illness severity is emphasised rather than patients' cognitive impairment.

Interestingly, it was found that the average length of patients' doctor and nurse contacts peaked for all four types of professionals (GPs, Nurses, old-age psychiatrists and other specialists) during the second quartile. This phenomenon cannot be explained with a seasonal effect since participants were continuously enrolled into the study and the second quartile translates into different months of the year depending on the enrolment date. This raises the important issue of ongoing support beyond the diagnosis. As discussed in section 6.7.8 (p. 349), some caregivers commented that the contact with the researcher was a very (if not the most) important support they had during the 12 months assessment period. It seems needless to point out that the different stages of dementia require different caregiving aspects which in turn call for different coping mechanisms. For the same reason, Qualls (2008) developed a concept of six different stages of the "family caregiving career" which express how informal caregivers adapt to the different levels of decline of the PWD.

During the study period, once patients were diagnosed with dementia in the memory clinic or another branch of the CDHB's Psychiatric Service for the Elderly (PSE), they were discharged if there were no complications requiring ongoing treatment present, such as neuropsychiatric behaviours requiring medication. Patients requiring further treatment were either treated by the same service or referred on to another PSE service as required. In many cases, support options such as day care were allocated after a needs-assessment was completed and reassessments were automatically arranged for no more than 12 months later. All support service allocations were

clearly communicated to the care recipients and their families by letter, including the provision for re-assessment in future. The Memory Clinic gave all patients an "Assessment Summary Letter" following their diagnostic process irrespective of whether or not they were being discharged. Other services such as the PSE Community Team did not routinely give such letters to patients and their families, relying instead on face to face communication. Discharge letters from all services were generally only sent to the relevant GP. These letters typically outlined the route for re-referral to specialist services if significant changes occurred or further questions arose.

However, at follow-up, the researcher was often asked about the further procedure not in terms of the concluded study but in terms of professional formal support for the PWD and the caregivers themselves. Caregivers also seemed often unaware of the role of their (or the PWD's) GPs as the most important link to the specialist services of the memory clinic. A follow-up phone call 6 to 9 months after the initial diagnosis might be a time- and cost-efficient solution to fill this information gap. Such a phone call could easily be made by a nurse from the GPs' practise, saving time and money of the more expensive specialist services.

6.5.3 Educational supports/interventions

It could not be determined whether, as expected, the utilisation of educational supports and interventions improved PWDs' QoL over time since none of the 19 caregivers who had provided data using the diaries was still attending any of the seminars offered by the Alzheimer society at the end of the year.

It could further not be determined whether the utilisation of educational supports and interventions positively impacted on PWDs' neuropsychiatric and behavioural symptoms and QoL. Nonetheless, a trend was shown that this type of intervention might have positively impacted on PWDs' neuropsychiatric and behavioural symptoms and QoL (proxy rated). So, even if the hypothesis was not clearly supported, the results were still in its favour. This finding supports earlier research where a combination of caregiver education regarding dementia and patients'

neuropsychiatric and behavioural symptoms in particular together with a long-term (6 months) caseworker support led to significant reductions in frequency and severity of difficult behaviours (Chien & Lee, 2008; Teri, et al., 2005). At the same time, caregivers' reactivity to those symptoms and behaviours (Teri, et al., 2005) and QoL (Chien & Lee, 2008) improved.

Seminars offered by Alzheimers Canterbury did not seem to improve caregivers' depression, burden or reactivity to difficult behaviours. Yet, even if this hypothesis was not clearly supported the results were in its favour. Caregivers who went to these seminars rated their own and the patients' QoL higher and they felt more supported by family and friends than other caregivers. These findings are consistent with those of other studies (R. Burns, et al., 2003; Chien & Lee, 2008; Kuzu, et al., 2005; Perren, et al., 2006; Teri, et al., 2005) and suggest that educational interventions (especially when combined with other support components) have a positive impact on caregiver and patient outcomes.

Finally, contrary to expectations, the utilisation of educational supports and interventions did not seem to improve caregivers' QoL over time. However, none of the 19 caregivers who had provided data using the diaries was still attending any of the seminars at the end of the year which limited the analysis.

6.5.4 Social supports/interventions

It was unexpected to find that the utilisation of social supports (day care, sitter service and support groups) and interventions did not seem to improve PWDs' QoL over time. Nevertheless, this result supports a systematic review conducted by Lee and Cameron (2004), who found no evidence for the efficacy of respite care for PWDs or for their caregivers. However, Lee and Cameron (2004) warned that these results "might reflect the lack of high quality research in this area rather than an actual lack of benefit" (pp. 1,2). In a similar way, the following section also contains a discussion of methodological issues as possible reasons for this study's unanticipated

result regarding social supports. Moreover, it has to be emphasised that there were also some positive trends observed.

Day care: It was found that caregivers of PWDs using day care showed a trend to have a lower burden score than others. But this could not be detected as a significant change over time but only as a group difference at follow-up. It has to be taken into consideration that the analysis was based on only 5 PWDs attending day care at baseline (9.6%) and 6 PWDs attending day care at follow-up (18.8%).

Sitter service: Unlike day care, caregivers of patients with sitter service rated their own QoL lower and rated the patients QoL lower at follow-up compared to other caregivers. Utilisation of a sitter service was very low and the analysis therefore limited (1.9% at baseline, 18.8% at follow-up).

Support groups: Even though the data did not support the hypothesis that attending a support group would improve patients' or caregivers' QoL over time, there are a number of possible explanations other than the inefficacy of the intervention:

- PWDs' rate of attending a support group was very small, with only 14.3% at baseline and 5.0% at follow-up. The same applies to caregivers' support group. The attendance rate was slightly higher with 26.2 % at baseline and 15.0% at follow-up. It is possible that these numbers were too small to detect significant differences between attendees and non-attendees.
- Also, as discussed in the previous chapter, the data suggested that caregivers who attended a support group provided less informal caregiving time and felt as a result less burdened and distressed enabling those caregivers more easily to participate in such an intervention. This finding supports outcomes of a recent study conducted in Europe. The authors of the EUROFAMCARE group found that caregivers accessed support services more often if they had a stronger support network and were less burdened (Lamura, et al., 2008).

The data also suggested that patients with more and more severe neuropsychiatric and behavioural symptoms (total NPI score) attended day care more often within the 2 weeks prior to follow-up than other patients. However, at the same time these participants had fewer sitter service contacts. The data further implied that patients who received a sitter service at baseline and who were more functionally impaired than others discontinued the study leaving patients who were more able to function independently. Taking these findings together they pose the question if neuropsychiatric and behavioural symptoms as well as decreased functioning are possible barriers to access sitter service. This could be an intervention which might provide important respite especially to caregivers of patients with neuropsychiatric and behavioural symptoms. The current study showed that neuropsychiatric and behavioural symptoms as well as functional impairment increased significantly at follow-up and caregivers of those patients were more burdened, depressed and distressed. Similar to sitter service, at follow-up there was a trend that caregivers who attended a support group looked after PWDs who had lower depression and NPI rates. Again, it seems that neuropsychiatric and behavioural symptoms create a barrier for caregivers to access important support services.

And even if the utilisation of social supports and interventions did not seem to improve PWDs' and caregivers' QoL over time (day care, sitter service and support groups) in this study similar to previous research (Belle, et al., 2006; Brodaty & Low, 2004; Droes, et al., 2004; B. G. Vickrey, et al., 2006), indications were found which support the hypothesis that a single intervention is less effective than a multi-component intervention. In this current study, combined information and support interventions were linked with significantly better patient QoL than single interventions. PWDs who used two interventions rated their QoL statistically significantly higher than other PWDs. This was consistent with caregivers' proxy ratings of patients' QoL. There was also a trend that caregivers who attended educational seminars, support groups and received counselling felt that they had a better QoL and that they were more supported by family and friends than caregivers who utilised fewer or none of these interventions.

6.5.5 Psychological supports/interventions

It was unexpected to find that the utilisation of psychological supports and interventions did not seem to improve PWDs' or caregivers' QoL during the 12 months. However, it was found that counselling for patients had a positive impact on patients' depression levels and caregivers' burden and possibly on distress levels. This finding is consistent with outcomes of a recently published Swedish study where "caregivers rated different types of support/services within the areas of information, relief and counselling as very important" (Alwin, Oberg, & Krevers, 2009).

Also, the data regarding participants' utilisation of psychological interventions were collected using only the diaries. Therefore, there is risk that the study might have missed out on a number of participants who possibly took advantage of this type of intervention but who did not send in their diaries. Finally, utilisation rates were reduced close to zero very early into the study (at the second quartile).

6.5.6 Non-pharmacological supports/interventions

It could not be determined whether, as predicted, non-pharmacological interventions are most effective when they are not only directed at the PWD but also at the caregiver since, to the researcher's best knowledge, none of the formal interventions available in Canterbury is explicitly designed to be directed at both. However, a significant difference was found between one group, in which only PWDs utilised one of the non-pharmacological interventions, and another group, in which PWDs and caregivers utilised an intervention. PWDs' NPI was significantly lower at follow-up when not only patients but also their caregivers utilised one of the non-pharmacological interventions.

6.6 Costs

Many people living with dementia in this study were reliant on welfare benefits as their main source of income and most participants (45.3%) fell into the lowest of three income categories, having a joint income/pension of less than NZ \$25,000 per year. There were two main in-cash

benefits that people with dementia received – the Invalids Benefit for those under 65 years of age and the aged pension (known as New Zealand Superannuation) for those 65 years of age and over. Moreover, the Community Services Card entitled the holder to price reductions of medical and community services such as GP visits and bus fares.

Most participants held a community services card. Still, 1 in 5 (22.6%) PWDs and 41.5% of caregivers did not hold a community services card. One-way ANOVA showed no significant differences between PWDs being card holders and those who did not have a Community Services Card regarding their medical service utilisation. Therefore it seems that not holding a Community Services Card is no barrier for PWDs to access medical services.

However, some differences were observed for caregivers. A trend was observed that caregivers with a Community Services Card were more likely to have seen a medical professional, to have been hospitalised and to have been taking mental health medication within the 3 months prior to the baseline assessment than non-card holders. Further analysis showed that these utilisation differences were not income related. The increased utilisation of medical professionals and hospitalisation could be explained by an increased age of caregivers who held a Community Services Card (Pearson's correlation: $r = -.580, p < .001$). Nevertheless, such an association was not found between carers' age and their utilisation of mental health medication. It can therefore be concluded that not having a Community Services Card is a barrier for caregivers of PWDs to access medication that might be vital to their own mental health status.

Interestingly, caregivers with a Community Services Card also rated their QoL significantly lower. Pearson's correlation showed that caregivers who held a Community Services Card not only were older but also more likely to live with the PWD ($r = .493, p < .001$), be a spouse ($r = .462, p = .001$), have a low income ($r = .665, p < .001$) and be in no paid employment ($r = -.719, p < .001$). The latter two associations are not surprising, since retired elderly are unlikely to be in paid employment and more likely to live of their pension. Being a spouse and living with the PWD is also not surprising if Community Services Cardholders are significantly older than other caregivers.

However, Pearson's correlations were also observed between living together with the PWD and having fewer formal care contacts ($r = .506, p < .001$), and being a spouse and having fewer formal care contacts ($r = .437, p = .001$). Taking these findings together the conclusion can be drawn that despite having community services cards spouses who look after their wife or husband with dementia are less likely to ask for formal support than children of PWDs. This might explain why caregivers who hold a Community Services Card rate their QoL lower. But this conclusion has to be treated with caution, since the data also showed that spouses were likely to look after patients who were less cognitively (Pearson's correlation with 3MS: $r = -.438, p = .001$) and functionally (Pearson's correlation with BADLS: $r = .305, p = .028$) impaired than patients who were cared for by children or friends.

6.6.1 Direct non-medical costs (except informal caregiving hours)

It was unexpected to find that direct non-medical costs of PWDs living at home (in-home care, out-of-pocket expenses such as transfer to doctor appointments, etc.) did not increase with the severity of patients' cognitive impairment. However, both direct medical and non-medical costs did increase with increasing dementia severity, increasing behavioural symptoms or increasing functional limitations. It was further established that the stage of dementia as well as the level of functional impairment were the best predictors of an increase in formal care utilisation and consequently of an increase in direct costs (not informal care). Also, the hypothesis on the impact of cognitive impairment on costs was derived from a study conducted in Belgium (Andrieu, et al., 2007). There, the study population consisted of PWDs at all stages of dementia, with participants being spread across the different severity groups more evenly than in this current study. It might be that the stage of dementia and the level of patients' functional impairment are better predictors of direct non-medical costs than patients' level of cognitive impairment at least at an early stage of illness.

6.6.2 Direct non-medical costs: informal caregiving hours

Interestingly, it was found that patients who received more informal care were more likely to rate their QoL lower. This outcome raises the question of cause and effect. It is unlikely that there is a direct causal relationship in which these patients received more informal care because they rated their QoL lower. Instead, QoL can be understood as a multi-dimensional construct which predicts impairment or reduced well-being in a number of aspects related to the dementia such as social, physical and economic components. An alternative to the above interpretation, the data also suggested that patients had a lower QoL because a higher informal care level put a higher burden on caregivers. The data showed that increased informal care had a significant negative impact on caregivers' psychological health (increased burden, distress and depression scores) which consequently also negatively impacted patients' QoL (lower QoL ratings, increased depression scores).

One of this study's unexpected economic results was that caregiving hours did not seem to have a significant negative impact on caregivers' physical health, which is contrary to earlier research (Markowitz, et al., 2003). However, Markowitz, et al. found only modest associations between informal caregiving hours and caregivers' physical health. The authors observed stronger associations with caregivers' mental health (Markowitz, et al., 2003). This is supported by the negative impact of informal care on caregivers' psychological health observed in this current study which was also found in other studies' findings (Covinsky, et al., 2003; O'Shea, 2003). It can be concluded that within the first year after patients' diagnosis of dementia the level of informal care affects first and foremost their family-caregivers psychological well-being. It may be that this phenomenon is an expression of caregivers' coping process which is driven to a certain extent by coming to terms with the diagnosis during this time. It is also possible that the fact that caregivers were on average 10 years younger than PWDs had an impact on their health status.

From the results of this study it can be concluded that reducing the intensity of informal care - by treating depression and neuropsychiatric and behavioural symptoms in PWDs - might reduce

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caregivers' symptoms of depression and burden with potential to delay institutionalisation and reduce costs.

6.6.3 Indirect costs: productivity costs

It was unexpected to find that indirect costs (here: productivity costs) did not increase with increasing dementia severity and behavioural symptoms, or with decreasing functional and cognitive abilities. However, it has to be taken into consideration that there were probably not enough participants enrolled in this study to split the data into meaningful groups and that the analysis and the conclusions that could be drawn from the data were limited.

The majority of caregivers in this study (71.4%) were able to work without having to take time off to care for the PWD during the 2 weeks prior to the interview. However, almost one-third (28.6%) of those in paid employment could not work up to 6 days during the 2 weeks prior to the assessment because they had to care for the PWD. This is an average of 0.6 days per caregiver within 2 weeks (12 days * divided by 21 caregivers in paid employment). Between baseline and follow-up assessments 6.7% of caregivers cut their weekly hours down to care for the PWD. So, even if the limited amount of data available here did not support the hypothesis that indirect costs increase with dementia severity and behavioural symptoms (as well as with decreasing functional and cognitive abilities), the data still showed that being a caregiver of a PWD impacted on caregivers' ability to earn an income from paid employment.

6.6.4 Perceived individual economic burden

As expected, and consistent with previous research (Covinsky, et al., 2003), caregivers were at much higher risk to become depressed if they had a low income. Interestingly, the results of Covinsky, et al.'s (2003) study conducted in 5000 patients with moderate to advanced dementia and their families are also applicable in samples of persons with primarily mild dementia. It was found in this current study that all caregivers with a low income more likely to be depressed regardless of the stage of dementia of their care recipients. This finding further supports

outcomes from a large recent survey conducted in Connecticut (Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009) where in a heterogeneous sample caregivers with inadequate income were at a four times higher risk to have depressive symptoms than caregivers with a sufficient income.

It could not be determined here if caregivers who were highly burdened considered that their financial situation is one of the most important determinants of their QoL which was hypothesised by the primary investigator in accordance with earlier research (Coen, et al., 2002). Nonetheless, it was found that caregivers' financial situation was still an important factor. Caregivers who felt financially more strained also rated their own QoL lower and they were more burdened and distressed. Moreover, more than one-third (39.5%) of caregivers would have liked to receive financial assistance, believing that this would enable them to take care of their relatives and friends with dementia at home for longer.

It has to be discussed here that the Cost-of-Care-Index (CCI) might not have been the most suitable instrument to assess dementia caregivers' perceived economic burden. At the time, the researcher chose this scale because it was one of very few identified to deal with individual economic burden rather than the societal approach. In comparison with the other scales, the CCI was the one which focussed on financial consequences of caring for an elderly person rather than the generic stress outcomes of life events such as work loss (Pearlin, Lieberman, Menaghan, & Mullan, 1981) and was more often cited than the Financial Impact Scale (Todtman & Gustafson, 1992). As outlined in the introduction of this thesis, van den Berg, et al. (2004) clearly noted the lack of instruments to incorporate informal caregivers' well-being and the cost of the care they provide into economic evaluations. In an effort to overcome this methodological gap, Brouwer, van Exel, van Gorp, and Redekop (2006) developed the CarerQoL instrument which also incorporates items regarding carers' financial burden. However, the published study was only a first evaluation of the new instrument applied to a heterogeneous caregiver population and

therefore considered unsuitable for this current research. It does, nevertheless, show that first efforts have been made to a more comprehensive approach where non-economic and economic aspects of caregiving and QoL in dementia are considered.

The following conclusion may be drawn from this study's economic findings:

1. Financial aspects including participants' individual economic burden should be assessed in QoL studies.
2. It is important to evaluate not only direct medical but also non-medical and indirect costs in dementia studies.
3. Income is an important and often overlooked predictor of QoL in dementia.
4. Developing (financial) incentives that reward informal caregivers for their time spent caring could be a key factor in supporting carers in their role. This might delay the need for permanent professional care and therefore decrease the societal financial burden.

6.7 Strengths and limitations of this study

The following section outlines some strengths and limitations of this study. These considerations provide an important frame in which the data analysis and the conclusions drawn from it should be understood.

6.7.1 Number of participants and time constraints

Different than predicted, not 100 dyads of PWDs and their caregivers but only 53 dyads could be enrolled into the study. Limited numbers resulted in a number of methodological issues:

- A number of hypotheses could not be determined due to low statistical power.
- Low statistical power was possibly also the reason why some hypotheses were not supported when they could be expected to be supported if data from more participants were available.

- For example, the hypothesis that indirect costs increase with dementia severity and behavioural symptoms (as well as with decreasing functional and cognitive abilities) was not supported by the data. However, there were probably not enough participants to split the data into meaningful groups.
- The limited sample size also restricted the range of scores and the generalisability of current findings.
- The small number of subjects and the large number of correlations and comparisons raise some concern about the potential occurrence of type II errors whereby a hypothesis might have been inappropriately retained.
- It has to be acknowledged that proof of causality was beyond the scope of this thesis.
 - For example, the analyses of hypothesised benefits of formal services was based on a small number of subjects who completed the 12-month assessment ($n = 32$), and many of the services included were used only briefly or only by an even smaller number of participants. Thus, this part of the analysis is rather exploratory than definitive.

Time and personnel constraints resulted in some further limitations. The analysis of the tape-recorded interviews (qualitative data) could not be carried out within the scope of this study and were postponed until after completion of this thesis. Also, some of the data could have been analysed in more depth. For example, controlling for socioeconomic and demographic variables would have provided a more complete picture of factors best predicting the QOL-AD scores (stepwise regression analyses).

Nevertheless, results of this study provide preliminary data and raise a number of potential areas for future research.

6.7.2 Data collection in Canterbury vs. data collection in New Zealand

Data were only collected in Canterbury with a majority of participants living in Christchurch (83.0%) and only some living in the more rural areas. The study results therefore are representative for Canterbury and Christchurch in particular but not necessarily for New Zealand in general. With an estimated 69.3% of the Canterbury population living in Christchurch in 2006, this sample underrepresented the rural population. Nevertheless, this is an important aspect because it highlights that in this study PWDs and their families living in rural areas accessed specialist mental health services not as frequently as patients from Christchurch. Living in rural Canterbury (or possibly New Zealand) therefore poses a likely barrier of accessibility of specialist mental health services for PWDs and their families.

6.7.3 Recruitment of participants through a memory clinic

This study was quasi-randomised enrolling the first 53 persons diagnosed with dementia and the caregivers willing to participate. However, most patients were recruited through the specialised psycho-geriatric services of The Princess Margaret Hospital in Christchurch. This resulted on the one hand in a cohort whose strength it was that all its members had been diagnosed in a similar way. On the other hand, it resulted in a certain bias excluding those persons who never receive a diagnosis of dementia and who do not (have) access to treatment.

6.7.4 Severity of dementia

Representativeness of the study sample was also slightly limited, since 83% of patients enrolled had mild dementia, 15% moderate and 2% severe dementia. The nationwide numbers were estimated at 55% mild dementia, 30% moderate and 15% severe dementia (Access Economics, 2008). In comparison, these nationwide estimates are spread more evenly across the different stages of dementia than in this study. However, at the same time it was also a strength of this study that the majority of patients were at an early stage of their dementia at baseline. Enrolling persons at an early stage provided the researcher with the opportunity to observe the change in illness progression during 1 year. As shown in section 5 of the previous chapter, dementia

progression was one of the factors predicting the discontinuation of participants in the study. Enrolling more participants at a later stage would therefore have increased the likelihood of losing participants to follow-up.

A sample consisting mainly of early dementia patients was also a strength because fewer studies have been conducted in such a population. The call for early diagnosis and early interventions (at an early stage of dementia) is growing louder but has not been met by a respective proportion of studies yet.

6.7.5 Collection of data using only diaries

Some hypotheses were not supported when they could be expected to be supported if data had been collected not only using the service use and costs diaries but also the Service Use Questionnaire. This applies to formal care interventions such as educational seminars, support groups and counselling.

Additionally, caregivers' productivity costs were assessed using the Service Use Questionnaire at baseline as well as the costs diaries during the 12 months. However, days of work lost due to their caregiving responsibilities were not assessed again at follow-up with the questionnaire. Because the return rate of the diaries had dropped to 60.6% at the fourth quartile, calculations of indirect costs would have reflected caregivers' reality more accurately if these costs had also been assessed at follow-up by administering the questionnaire to all carers. However, the work status questionnaire gave important insight at follow-up regarding carers' cut back of working hours to look after the PWD.

6.7.6 Measuring of caregivers' depression levels using the GDS

The GDS might not be suitable to assess depression levels in caregivers of PWDs. The scale was originally developed for use with older persons. Despite the fact that the scale has been applied successfully in populations of younger and older family-caregivers of PWDs (chapter 4.7.3.4, p. 141) the results obtained in this study were somewhat limited. It might be necessary to develop a dementia-specific scale to measure caregivers' depression levels.

However, overall it was a strength of this study that all but one of the outcomes were assessed using widely accepted and well validated instruments. Patients' and caregivers' health status was assessed using a scale developed to measure the impact of participants' health (other than the dementia) on their QoL. As outlined earlier (4.7.2.7, p. 139), a number of validated instruments exist which were either too time consuming to administer or required specialised medical knowledge which could not be provided by the researcher. The health status scale was easy to administer and did not take longer than 5 to 10 minutes to complete.

6.7.7 Role of the researcher

It is a strength of this study that almost all data were collected by the same researcher. As outlined in section 4 of the methodology chapter (p. 125) some of the baseline data (3MS, NPI, NPI-D, BADLS) were collected as part of the routine diagnostic process at The Princess Margaret Hospital (TPMH). However, this only applies to those patients who had been referred to the study by the Memory Clinic of TPMH and not by the community team.

It should also be known that the researcher drew the initial motivation for this study from her own personal experience with dementia in her family. It could be argued from a conservative point of view that such experience might endanger the objectivity of the investigator. However, it could also be seen as strength enabling the researcher to connect with study participants in a meaningful and honest way thus providing high quality data.

6.7.8 The study as an intervention

Feedback provided by some of the participants about the contact they had with the researcher during the year, being a very (if not the most) important support, needs to be addressed. As much as this is a very positive and reassuring feedback it also raises the question to what extent this study was an intervention in its own right. In addition to the two assessments, there was often a considerable amount of time involved where the researcher would contact participants to remind them to send in the diaries or react to questions or information written down in the monthly diary

sheets. Part of these phone calls would usually be an opening question of how the participant was and how the situation was developing with regards to the dementia. Often the researcher would provide information and practical advice on how to cope with a situation depending on the level of burden or lack of information communicated. For example, in several cases caregivers planned to go on holidays either with or without the PWD and they would note this (as requested) in the diaries so the researcher knew not to expect diaries for this period of time. More than once caregivers raised their concerns about their trips. It is the authors' opinion that it is an ethical obligation to provide such support and information. However, it also needs to be stressed that whenever the situation raised serious concerns about the participants' health or well-being or coping abilities, the investigator would recommend to contact the professional involved (such as GPs or TPMH staff). In some cases participants welcomed the researcher's offer to initiate such a contact.

This example shows not only how important it is for researchers to become aware of the position they take in such a study, it also indicates that there seems to be a barrier for caregivers of PWDs in Canterbury to contact health care professionals when they need to. Possible explanations could be that caregivers feel their concerns related to the care of the PWD are not important enough to justify such contact. Or they might not know whom to contact. Considering that all study participants have been enrolled through TPMH and that many were referred to the Alzheimer society it is surprising that such a barrier still existed. For the future it could be important for health professionals and social workers alike to clarify their role in the care of PWDs. However, it also has to be emphasised that professionals in the field of dementia might be reluctant to strongly advocate their services because of their limited resources.

7 Implications

This study leads to a number of implications on different levels for clinicians, for organisations involved in the support and delivery of dementia care and for policy makers in New Zealand.

1. QoL in PWDs and their family-caregivers is predicted by a variety of clinical and non-clinical factors: **multi-dimensional concept**
2. QoL of PWDs and their caregivers is closely linked. PWDs' QoL should also be understood in the context of their caregivers' QoL: **systemic approach**
3. **Economic aspects** should be considered in QoL studies including the participants' individual economic burden, and the assessment of direct and indirect costs. The concept of QoL will possibly be more viable and relevant for policy makers if it can be translated into costs.

7.1 Implications for clinicians

Applying the **multi-dimensional concept** to the busy routines of daily clinical work might seem unrealistic. However, it could be simple steps such as emphasising to colleagues and experts that QoL is by now a primary outcome in dementia care which requires more than a cognitive screening test. Cognitive impairment is an important indicator but should not become the sole focus when deciding on further health system steps. This is not so much an issue with expert institutions such as memory clinics, but more with less specialised care providers. For example, if a PWD is diagnosed with dementia while being admitted to hospital care for a primary reason other than the dementia, the hospital staff needs to be trained in following or initiating steps to ensure sufficient care and support for the PWD and the family-caregiver beyond the hospitalisation.

Acknowledging QoL as a primary care outcome also requires the actual assessment of PWDs' QoL as part of the diagnostic routine. Further, better integration of primary and secondary care is likely to strengthen the support of PWDs' and their caregivers as the condition progresses. Such

improved integration is currently under way in Christchurch, albeit at an early stage of development, and has important implications for enhanced delivery of patient-centred care.

A **systemic approach** might translate into using a short QoL questionnaire such as the QOL-AD to not only assess patients' QoL but also their caregivers' well-being. The QOL-AD does not have to be administered in interview form but could be completed by the primary informal caregiver while waiting for the patients' assessment results. Such an assessment might provide indicators of caregivers' coping ability and if caregivers are at risk to develop clinical symptoms such as depressive symptoms themselves.

Regarding **economic aspects**, clinicians might be able to take note if a family's socio-economic background impacts on their decision to access health care services and supports such as dementia medication. Even if clinicians are not in the position to change anything about this, such data might become a key argument in the discussion with policy makers about provision of funding and substitution for supports and interventions.

7.2 Implications for service providers

For service providers such as the Alzheimer society, the **multi-dimensional concept** could translate into developing interventions and supports which aim at sustaining or improving the QoL of PWDs and their informal caregivers. Interventions, which target PWDs' depressive, neuropsychiatric and behavioural symptoms showed promising outcomes overseas. Even though this study could not clearly determine if social, psychological and educational interventions can help to sustain or improve QoL, consistent with overseas research, this study showed that combined interventions are more likely to be effective than single interventions. A case management approach combined with education towards such symptoms could be considered to be implemented in New Zealand. This study's data suggest that such an approach might overcome barriers to access already available supports.

Taking a **systemic approach**, service providers might want to focus on developing support concepts which embrace the unit of PWDs and their informal caregivers. Similar to overseas research, this study found promising indications that non-pharmacological interventions are more effective if not only directed at the PWDs but also at their caregivers.

7.3 Implications for policy makers

Many outcomes of the recent economic report issued by Alzheimers New Zealand (Access Economics, 2008) had to be based on overseas data since no sufficient data were available for New Zealand. Similarly, it was noted in the systematic review (chapter 2 of this thesis) that no New Zealand study could be identified for any of the clinical, care or economic aspects investigated. It is therefore crucial to provide funding for research and development of nationwide databases. This will be the foundation to the development and implementation of nationwide standards and guidelines regarding dementia diagnosis, dementia care and service delivery. For example, New Zealand yet has to agree on standards for the diagnostic process as well as a definition of dementia-specific residential care. In order to be able to face the growing epidemic, working in age related care has to become more attractive, for example by raising the minimum salary. Specialist centres, such as memory clinics, have to be accessible beyond the three major urban areas. Setting up “mobile memory clinics” should be considered. Such a service could also be a step towards resolving the ongoing discussion of how to take pressure away from hospitals and direct patients towards secondary care. In the case of dementia the following scenario is possible:

- Question: How can detection and treatment of dementia in primary care be improved?
- Aim: Detection and treatment of PWDs earlier to avoid hospitalisation (because of currently inadequate community based care) and delay residential care admittance.

- Method: Build expertise around GPs with an expert team (which could be mobile) which could consist of a neurologist or psychiatrist, nurse, social worker (for example from Alzheimers New Zealand), and/or psychologist.
- Predicted outcome: A combination of nurse/GP education as well as walk in sessions offering initial diagnosis/referral to specialist services if necessary, and case management from day one with long-term support. This will increase the detection rate of PWDs living in the community, reduce avoidable hospitalisation of PWDs and their informal caregivers, sustain patients' and caregivers' QoL for longer and in certain aspects improve it, thus delaying admittance into permanent care.

It has to be noted that this is only a small scale example of how an **interdisciplinary, multi-dimensional systems approach to health care** might have the potential to improve outcomes for PWDs, their caregivers, as well as medical professionals and service providers in New Zealand thereby **reducing long-term costs**.

Training and education, however, cannot stop with primary and secondary care organisations. The establishment of dementia-scholarships for studies in the fields of gerontology, neurology, social sciences, psychology and health sciences would most certainly create vital, New Zealand-based knowledge which in turn would increase this country's preparedness for dementia.

Last, but not least, raising the awareness of dementia and increasing New Zealanders' sensitivity towards this illness and its consequences would help to reduce the stigma still attached to dementia. Similar requests have been raised only recently in Australia. Here, Low, et al. (2009) from the 'Dementia Collaborative Research Centres' suggested in a recent report the need to "identify, develop and evaluate model/s to improve dementia literacy in the community" as one strategic future direction in dementia research. As a result, dementia might be diagnosed earlier, providing PWDs and their families with coping strategies that will probably delay admittance into permanent care.

8 Future research

Based on this study's limitations, future research should investigate:

1. how QoL changes over longer time periods such as 5, 10 or 15 years;
2. if this current study's findings are repeated in larger (nationwide) samples which also include PWDs in rural areas;
3. if this current study's findings are repeated in ethnically and culturally diverse samples, with regards to the New Zealand population, especially in Maori, Pacific Islander and Asian PWDs and their caregivers;
4. the barriers for PWDs and their families to access care (GPs, hospitals, community services and residential care), such as socio-economic status, rural residence, PWDs' symptoms;
5. how QoL changes in relation to specific interventions available in New Zealand.

It is noteworthy that the recent economic report (Access Economics, 2008) concluded that "no epidemiological studies of dementia incidence or prevalence in the New Zealand population or in specific ethnic groups within the population were identified" (p. 8). The report's authors further recommended: "It would be worthwhile collecting such information, particularly in ethnic groups such as Maori and Pacific Island people, since it is possible that dementia prevalence rates differ by ethnicity" (p. 8).

Additionally, or more specifically, a number of hypotheses could not be determined based on data from this current study. Since all hypotheses for this study were derived from studies conducted elsewhere but in New Zealand, future research could aim at verifying these hypotheses:

1. Early diagnosis results in decreased patients' neuropsychiatric and behavioural symptoms.
2. The utilisation of educational supports and interventions improves PWDs' QoL over time and positively impacts on PWDs' neuropsychiatric and behavioural symptoms and QoL.
3. Non-pharmacological interventions are most effective when they are not only directed at the PWD but also at the caregiver.

4. Direct medical costs of PWDs living at home increase with the severity of patients' cognitive impairment.
5. Caregivers who are highly burdened consider that their financial situation is one of the most important determinants of their QoL.

Future studies will crucially depend on raising the current expenditure on dementia related research from NZ \$2.9 million (0.41% of the financial costs of dementia) to at least NZ \$7.1 million (1% of the total costs of dementia) per annum as recommended in the report previously cited (Access Economics, 2008). "Research that prevents onset of dementia would substantially reduce the cost of care, and there is a particular need for research into care services tailored to the New Zealand environment, and epidemiological research for Maori and Pacific people" (Access Economics, 2008) (p. vii). This thesis will hopefully provide a basis for such future research.

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Appendices

Appendix A: Included papers level-1

- Aisen, P. S., Schafer, K. A., Grundman, M., Pfeiffer, E., Sano, M., Davis, K. L., et al. (2003). Effects of rofecoxib or naproxen vs placebo on Alzheimer disease progression: a randomized controlled trial. *JAMA : the journal of the American Medical Association*, (291), 2819-2826. Retrieved from <http://www.mrw.interscience.wiley.com/cochrane/clcentral/articles/022/CN-00438022/frame.html> **Included (Drug + QoL). Included.**
- Banerjee, S., Smith, S. C., Lamping, D. L., Harwood, R. H., Foley, B., Smith, P., et al. (2006). Quality of life in dementia: more than just cognition. An analysis of associations with quality of life in dementia. *J Neurol Neurosurg Psychiatry*, 77(2), 146-148. **Included. Included.**
- Banerjee, S., Willis, R., Matthews, D., Contell, F., Chan, J., & Murray, J. (2007). Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model. *Int J Geriatr Psychiatry*, 22(8), 782-788. **Included. Included.**
- Droes, R. M., Meiland, F., Schmitz, M., & van Tilburg, W. (2004). Effect of combined support for people with dementia and carers versus regular day care on behaviour and mood of persons with dementia: results from a multi-centre implementation study. *Int J Geriatr Psychiatry*, 19(7), 673-684. **Included. Included.**
- Edelman, P., Fulton, B. R., & Kuhn, D. (2004). Comparison of dementia-specific quality of life measures in adult day centers. *Home Health Care Serv Q*, 23(1), 25-42. **Included. Included.**
- Ettema, T. P., Droes, R. M., de Lange, J., Ooms, M. E., Mellenbergh, G. J., & Ribbe, M. W. (2005b). The concept of quality of life in dementia in the different stages of the disease. *Int Psychogeriatr*, 17(3), 353-370. **Included. Included.**
- Fuh, J. L., & Wang, S. J. (2006). Assessing quality of life in Taiwanese patients with Alzheimer's disease. *Int J Geriatr Psychiatry*, 21(2), 103-107. **Included. Included.**
- Gitlin, L. N., Winter, L., Burke, J., Chernett, N., Dennis, M. P., & Hauck, W. W. (2008). Tailored activities to manage neuropsychiatric behaviors in persons with dementia and reduce caregiver burden: a randomized pilot study. *The American journal of geriatric psychiatry : official journal of the American Association for Geriatric Psychiatry*, (3), 229-239. Retrieved from <http://www.mrw.interscience.wiley.com/cochrane/clcentral/articles/086/CN-00638086/frame.html> **Included. Included.**
- Graff, M. J., Vernooij-Dassen, M. J., Thijssen, M., Dekker, J., Hoefnagels, W. H., & Olderkert, M. G. (2007). Effects of community occupational therapy on quality of life, mood, and health status in dementia patients and their caregivers: a randomized controlled trial. *The journals of gerontology. Series A, Biological sciences and medical sciences*, (9), 1002-1009. Retrieved from <http://www.mrw.interscience.wiley.com/cochrane/clcentral/articles/241/CN-00612241/frame.html> **Included. Included.**
- Hurt, C., Bhattacharyya, S., Burns, A., Camus, V., Liperoti, R., Marriott, A., et al. (2008). Patient and caregiver perspectives of quality of life in dementia. An investigation of the relationship

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- Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosom Med*, 64(3), 510-519. **Included. Included.**
- Matsui, T., Nakaaki, S., Murata, Y., Sato, J., Shinagawa, Y., Tatsumi, H., et al. (2006). Determinants of the quality of life in Alzheimer's disease patients as assessed by the Japanese version of the Quality of Life-Alzheimer's disease scale. *Dement Geriatr Cogn Disord*, 21(3), 182-191. **Included. Included.**
- Moniz-Cook, E., Vernooij-Dassen, M., Woods, R., Verhey, F., Chattat, R., De Vugt, M., et al. (2008). A European consensus on outcome measures for psychosocial intervention research in dementia care. *Aging Ment Health*, 12(1), 14-29. **Included. Included.**
- Ready, R. E., Ott, B. R., & Grace, J. (2004). Patient versus informant perspectives of Quality of Life in Mild Cognitive Impairment and Alzheimer's disease. *Int J Geriatr Psychiatry*, 19(3), 256-265. **Included. Included.**
- Ready, R. E., Ott, B. R., Grace, J., & Fernandez, I. (2002). The Cornell-Brown Scale for quality of life in dementia. *Alzheimer Dis Assoc Disord*, 16(2), 109-115. **Included. Included.**
- Shin, I. S., Carter, M., Masterman, D., Fairbanks, L., & Cummings, J. L. (2005). Neuropsychiatric symptoms and quality of life in Alzheimer disease. *Am J Geriatr Psychiatry*, 13(6), 469-474. **Included. Included.**
- Snow, A. L., Dani, R., Soucek, J., Sullivan, G., Ashton, C. M., & Kunik, M. E. (2005). Comorbid psychosocial symptoms and quality of life in patients with dementia. *Am J Geriatr Psychiatry*, 13(5), 393-401. **Included. Included.**
- Teri, L., McCurry, S. M., Logsdon, R. G., & Gibbons, L. E. (2005). Training community consultants to help family members improve dementia care: a randomized controlled trial. *The Gerontologist*, (6), 802-811. Retrieved from <http://www.mrw.interscience.wiley.com/cochrane/clcentral/articles/327/CN-00553327/frame.html> **Included. Included.**
- Thomas, P., Lalloue, F., Preux, P. M., Hazif-Thomas, C., Pariel, S., Inscale, R., et al. (2006). Dementia patients caregivers quality of life: the PIXEL study. *Int J Geriatr Psychiatry*, 21(1), 50-56. **Included. Included.**
- Vogel, A., Mortensen, E. L., Hasselbalch, S. G., Andersen, B. B., & Waldemar, G. (2006). Patient versus informant reported quality of life in the earliest phases of Alzheimer's disease. *Int J Geriatr Psychiatry*, 21(12), 1132-1138. **Included. Included.**
- Woods, B., Spector, A., Jones, C., Orrell, M., & Davies, S. (2005). Reminiscence-therapy for dementia. *Cochrane Database Syst Rev*(2), CD001120. **Included. Included.**

Appendix B: Included papers level-2

a) Informal interventions; b) direct costs; c) indirect costs; d) financial burden

- Andrieu, S., Rive, B., Guilhaume, C., Kurz, X., Scuvee-Moreau, J., Grand, A., et al. (2007). New assessment of dependency in demented patients: impact on the quality of life in informal caregivers. *Psychiatry Clin Neurosci*, 61(3), 234-242. **Included. Included (IIb)**⁴⁰.
- Birks, J., & Harvey, R. J. (2006). Donepezil for dementia due to Alzheimer's disease. *Cochrane Database of Systematic Reviews*, (1). Retrieved from <http://www.mrw.interscience.wiley.com/cochrane/clsysrev/articles/CD001190/frame.html>. doi:10.1002/14651858.CD001190.pub2 **Included (Drug + QoL). Included (IIb)**.
- Boström, F., Jönsson, L., Minthon, L., & Londos, E. (2007). Patients with Lewy body dementia use more resources than those with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 22(8), 713-719. **Included. Included (IIb)**.
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- Burgener, S. C. (1999). Predicting quality of life in caregivers of Alzheimer's patients: the role of support from and involvement with the religious community. *J Pastoral Care*, 53(4), 433-446. **Included. Included (IIa)**.
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⁴⁰ Informal interventions (a); direct costs (b); indirect costs (c); financial burden (d)

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Appendix C: Ethical approval

LOCALITY ASSESSMENT – by Locality Organisation	
Refer to pp10-12 of the Guidelines for Completion of the National Application Form for Ethical Approval of a Research Project	
Full Project Title: Early intervention and quality of life of people with dementia and their family-caregivers living in New Zealand	
Short Project Title: Early intervention and quality of life in dementia	
Brief outline of study: <p>Aim of this study will be to evaluate the quality and efficiency of support which is offered by the New Zealand health system for dementia sufferers and their families. Outcomes will be the global QoL, per se plus various QoL dimensions (cognition, behaviour, depression, functioning, and burden). In addition both direct and indirect costs will be estimated of caring for dementia patients who live at home.</p> <p>We will examine the QoL of one hundred patients recently diagnosed with dementia and their family-caregivers receiving social, educational, psychological, and/or medical support. Interventions will be measured in hours by providing caregivers with a diary to record the amount and kind of intervention (in-home care, out-home care, one-to-one counselling, and group meetings). QoL and costs will be measured at baseline and after 12 months. Some direct and indirect costs will be also recorded in a diary by the caregivers for the duration of 12 months.</p> <p>The hypothesis is that providing family-caregivers and dementia-patients with professional support will result in an improved caregiver-patient interaction, decrease the carers' burden, increase the patient's-QoL and the caregiver's-QoL, and delay institutionalisation. On a long-term basis this could prevent and/or delay some of the costs associated with dementia.</p>	
Principal Investigator: Franziska Gallrach, PhD-Candidate (Health Sciences)	
Contact details:	
Franziska Gallrach 98a Perry Street Papanui Christchurch 8053 Email: FranziskaGallrach@web.de	OR Franziska Gallrach PhD student Health Sciences Centre University of Canterbury Private Bag, 4800 Christchurch 8020
Tel: Home: (03) 352-5250	Work: (03) 364-2987 ext.8362
Local investigators: As principal investigator	
Contact details: As above	
Locality Organisation signoff Ethics committees review whether investigators have ensured their studies would meet established ethical standards, if conducted at appropriate localities; each locality organisation is asked to use the locality assessment form to check that the investigator has also made the appropriate local study arrangements.	

- all serious adverse events occurring during the study worldwide which are considered related to the study medicine. Where there is a data safety monitoring board in place, serious adverse events occurring outside New Zealand may be reported quarterly.

All SAE reports must be signed by the Principal Investigator and include a comment on whether he/she considers there are any ethical issues relating to this study continuing due to this adverse event. It is assumed by signing the report, the Principal Investigator has undertaken to ensure that all New Zealand investigators are made aware of the event.

Amendments

All amendments to the study must be advised to the Committee prior to their implementation, except in the case where immediate implementation is required for reasons of safety. In such cases the Committee must be notified as soon as possible of the change.

Please quote the above ethics committee reference number in all correspondence.

The Principal Investigator is responsible for advising any other study sites of approvals and all other correspondence with the Ethics Committee.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

We wish you well with your study.

Yours sincerely



Alieke Dierckx
Upper South A Ethics Committee Administrator
Email: alieke_dierckx@moh.govt.nz



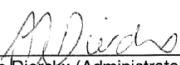
Upper South A Regional Ethics Committee

Ministry of Health
4th Floor, 250 Oxford Terrace
PO Box 3877
Christchurch
Phone (03) 372 3037
Fax (03) 372 1015

List of members of the Upper Region A Ethics Committee, June 2007

Carolyn Mason (Chair)	Ethicist/Philosopher Lay member	Female
Carolynn Bull	Legal representative, Maori representative Lay member	Female
John Horwood	Biostatistician Lay member	Male
Jane Kerr	Researcher Health Professional Member	Female
Alison Luckey	Health Practitioner Health Professional member	Female
Tom Marshall	Clinical Psychologist Health Professional member	Male
Ellen McCrae	Pharmacist Health Professional member	Female
Edie Moke	Maori representative Lay member	Female
Nicky Murray	Community Representative Lay member	Female
Elizabeth Richards	Consumer Representative Lay member	Female
Russell Scott	Health Practitioner Health Professional member	Male

Jane Kerr, Ellen McCrae and Edie Moke were not present at the meeting on 25 June 2007.
Sharon English, Health Practitioner, provided written comments in her capacity as expert advisor.


Alieke Dierckx (Administrator)

4/07/07
Date

Appendix D: Locality organisational approval

LOCALITY ASSESSMENT – by Locality Organisation

Refer to pp10-12 of the Guidelines for Completion of the National Application Form for Ethical Approval of a Research Project

Full Project Title:

Early intervention and quality of life of people with dementia and their family-caregivers living in New Zealand

Short Project Title:

Early intervention and quality of life in dementia

Brief outline of study:

Aim of this study will be to evaluate the quality and efficiency of support which is offered by the New Zealand health system for dementia sufferers and their families. Outcomes will be the global QoL *per se* plus various QoL dimensions (cognition, behaviour, depression, functioning, and burden). In addition both direct and indirect costs will be estimated of caring for dementia patients who live at home.

We will examine the QoL of one hundred patients recently diagnosed with dementia and their family-caregivers receiving social, educational, psychological, and/or medical support. Interventions will be measured in hours by providing caregivers with a diary to record the amount and kind of intervention (in-home care, out-home care, one-to-one counselling, and group meetings). QoL and costs will be measured at baseline and after 12 months. Some direct and indirect costs will be also recorded in a diary by the caregivers for the duration of 12 months.

The hypothesis is that providing family-caregivers and dementia-patients with professional support will result in an improved caregiver-patient interaction, decrease the carers' burden, increase the patient's-QoL and the caregiver's-QoL, and delay institutionalisation. On a long-term basis this could prevent and/or delay some of the costs associated with dementia.

Principal Investigator: Franziska Gallrach, PhD-Candidate (Health Sciences)

Contact details:

Franziska Gallrach
98a Perry Street
Papanui
Christchurch 8053
Email: FranziskaGallrach@web.de

OR

Franziska Gallrach
PhD student Health Sciences Centre
University of Canterbury
Private Bag, 4800
Christchurch 8020

Tel: Home: (03) 352-5250

Work: (03) 364-2987 ext.8362

Local Investigators: As principal investigator

Contact details: As above

Locality Organisation signoff

Ethics committees review whether investigators have ensured their studies would meet established ethical standards, if conducted at appropriate localities; each locality organisation is asked to use the locality assessment form to check that the investigator has also made the appropriate local study arrangements.

Ethics approval for study conduct at each site is conditional on favourable locality assessment at that locality.

Locality issues: (see guidelines for more information and examples)
Identify any local issues and specify how they will be addressed.

1. Suitability of local researcher

For example, are all roles for the investigator(s) at the local site appropriate (e.g. has any conflict the investigator might have between her or his local roles in research and in patient care been adequately resolved)?

Answer: The principal investigator is a PhD student in the Health Sciences Centre at the University of Canterbury. As such, she has no professional or clinical relationship with the target population other than that established for the purpose of data collection for her PhD study. There is no conflict of interest in undertaking the proposed research.

2. Suitability of the local research environment

For example, have the resources (other than funding which is conditional on ethical approval) and/or facilities that the study requires locally been identified? Are they appropriate and available?

Answer: The research environment is a University which is set up to carry out such research and has policies and practices in place to ensure a supportive environment is provided to the researcher. The University of Canterbury policy is to have a contract drawn up between the student and the supervisor with each other's roles and expectations clearly detailed.

3. What are the specific issues relating to the local community?

For example, are there any cultural or other issues *specific* to this locality, or to participants for whom study recruitment or participation is primarily at this locality? If so, how have they been addressed?

Answer: The study population is people with dementia and their families living in Christchurch. The researcher acknowledges that a mature level of sensitivity is required during any interaction that she has with this group.

4. Information sheet/consent form contact details:

Contact details for Health & Disability Consumer Advocates:

If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Services Consumer Advocate on 03 3777 501 or 0800 377 766 outside of Christchurch.

Contact details for any other important local services: N/A

I understand that I may withdraw locality approval if any significant local concerns arise. I agree to advise the Principal Investigator and then the relevant ethics committee should this occur.

Signature:

Name: Dr Jeff Kinnon

Contact details:

Date: 6/8/07

Position: Clinical Director, Older Persons Health
Canterbury District Health Board

Level 3, The Panmure Margaret Hospital

PO Box 800, CHRISTCHURCH

jeff.kinnon@cdhb.govt.nz

LOCALITY ASSESSMENT – by Locality Organisation

Refer to pp10-12 of the Guidelines for Completion of the National Application Form
for Ethical Approval of a Research Project

Full Project Title:

Early intervention and quality of life of people with dementia and their family-caregivers living in
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Early intervention and quality of life in dementia

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and burden). In addition both direct and indirect costs will be estimated of caring for dementia
patients who live at home.

We will examine the QoL of one hundred patients recently diagnosed with dementia and their
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Interventions will be measured in hours by providing caregivers with a diary to record the
amount and kind of intervention (in-home care, out-home care, one-to-one counselling, and
group meetings). QoL and costs will be measured at baseline and after 12 months. Some direct
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months.

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term basis this could prevent and/or delay some of the costs associated with dementia.

Principal Investigator: Franziska Gallrach, PhD-Candidate (Health Sciences)

Contact details:

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98a Perry Street
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OR Franziska Gallrach
PhD student Health Sciences Centre
University of Canterbury
Private Bag, 4800
Christchurch 8020

Tel: Home: (03) 352-5250

Work: (03) 364-2987 ext.8362

Local investigators: As principal investigator

Contact details: As above

Locality Organisation signoff

Ethics committees review whether investigators have ensured their studies would meet
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If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Services Consumer Advocate on 03 3777 501 or 0800 377 766 outside of Christchurch.

Contact details for any other important local services: N/A

I understand that I may withdraw locality approval if any significant local concerns arise. I agree to advise the Principal Investigator and then the relevant ethics committee should this occur.

Signature: *P. Hanne Ross*

Date: 29 May 2007

Name: P. Hanne Ross

Position: Manager

Contact details:

Alzheimers Canterbury
314 Worcester Street, P.O. Box 32 074
Christchurch.
Phone (03) 379 2590

LOCALITY ASSESSMENT – by Locality Organisation

Refer to pp10-12 of the Guidelines for Completion of the National Application Form for Ethical Approval of a Research Project

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We will examine the QoL of one hundred patients recently diagnosed with dementia and their family-caregivers receiving social, educational, psychological, and/or medical support. Interventions will be measured in hours by providing caregivers with a diary to record the amount and kind of intervention (in-home care, out-home care, one-to-one counselling, and group meetings). QoL and costs will be measured at baseline and after 12 months. Some direct and indirect costs will be also recorded in a diary by the caregivers for the duration of 12 months.

The hypothesis is that providing family-caregivers and dementia-patients with professional support will result in an improved caregiver-patient interaction, decrease the carers' burden, increase the patient's-QoL and the caregiver's-QoL, and delay institutionalisation. On a long-term basis this could prevent and/or delay some of the costs associated with dementia.

Principal Investigator: Franziska Gallrach, PhD-Candidate (Health Sciences)

Contact details:

Franziska Gallrach
98a Perry Street
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Christchurch 8053
Email: FranziskaGallrach@web.de

OR Franziska Gallrach
PhD student Health Sciences Centre
University of Canterbury
Private Bag, 4800
Christchurch 8020

Tel: Home: (03) 352-5250

Work: (03) 364-2987 ext.8362

Local investigators: As principal investigator

Contact details: As above

Locality Organisation signoff

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Contact details for any other important local services: N/A

I understand that I may withdraw locality approval if any significant local concerns arise. I agree to advise the Principal Investigator and then the relevant ethics committee should this occur.

Signature:  Date: 31/5/07

Name: G.W. Rountree. Position: General Manager.

Contact details:

LOCALITY ASSESSMENT – by Locality Organisation

Refer to pp10-12 of the Guidelines for Completion of the National Application Form for Ethical Approval of a Research Project

Full Project Title:

Early intervention and quality of life of people with dementia and their family-caregivers living in New Zealand

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Principal Investigator: Franziska Gallrach, PhD-Candidate (Health Sciences)

Contact details:

Franziska Gallrach
98a Perry Street
Papanui
Christchurch 8053
Email: FranziskaGallrach@web.de

OR Franziska Gallrach
PhD student Health Sciences Centre
University of Canterbury
Private Bag, 4800
Christchurch 8020

Tel: Home: (03) 352-5250

Work: (03) 364-2987 ext.8362

Local investigators: As principal investigator

Contact details: As above

Locality Organisation signoff

Ethics committees review whether investigators have ensured their studies would meet established ethical standards, if conducted at appropriate localities; each locality organisation is asked to use the locality assessment form to check that the investigator has also made the appropriate local study arrangements.

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3. What are the specific issues relating to the local community?

For example, are there any cultural or other issues *specific* to this locality, or to participants for whom study recruitment or participation is primarily at this locality? If so, how have they been addressed?

Answer: The study population is people with dementia and their families living in Christchurch. The researcher acknowledges that a mature level of sensitivity is required during any interaction that she has with this group.

4. Information sheet/consent form contact details:

Contact details for Health & Disability Consumer Advocates:

If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Services Consumer Advocate on 03 3777 501 or 0800 377 766 outside of Christchurch.

Contact details for any other important local services: N/A

I understand that I may withdraw locality approval if any significant local concerns arise. I agree to advise the Principal Investigator and then the relevant ethics committee should this occur.

Signature: *R. K. K.*

Date: 31-5-07

Name: *Dr. Ray K. K.*

Position: *Acad. Director HSC, UC*

Contact details:

Health Sciences Centre

Health

University of Canterbury

Appendix E: Support letter Maori and Pacific Health CDHB

Canterbury

District Health Board

Te Poari Hauora o Waitaha

*Executive Director, Māori & Pacific Health
Canterbury District Health Board
Level 2, H Block
The Princess Margaret Hospital
Cashmere Road
Christchurch*

17 July 2007

Franziska Gallrach, Ph.D.-Candidate
Health Sciences Centre
University of Canterbury

Tēnā koe e Franziska

Early Intervention and Quality of Life of People With Dementia and Their Family-Caregivers

Thank you sending me your research proposal on early intervention and quality of life of people with dementia and their family-caregivers.

I note the sensitive nature of the project the length of time taken to get the required approvals. I also note that this project has been through a rigorous ethics approval process and requires sign-off from an appropriate Māori spokesperson.

I am satisfied that the parameters of your project meet the ethical guidelines as they apply to Māori. In particular I am pleased that both consumer and whānau rights have been acknowledged in the project proposal.

I wish you the best and look forward to seeing the final results published.

Regards



Hector Matthews
Executive Director, Māori & Pacific Health
Canterbury District Health Board

Canterbury District Health Board, PO Box 1600, Christchurch

Appendix F: Ethical approval for amendments



29 January 2008

Ms Franziska Gallrach
98a Perry Street
Papanui
Christchurch 8053

Dear Franziska Gallrach,

Early intervention and quality of life of people with dementia and their family-caregivers living in New Zealand

Investigator: Ms Franziska Gallrach
Locality: The Princess Margaret Hospital
Ethics ref: URA/07/06/044

Amendment:

To include persons with severe dementia

The above amendment has been approved by the Chairperson of the Upper South A Regional Ethics committee under delegated authority.

Yours sincerely

Aleke Dierckx
Upper South A Ethics Committee Administrator

Upper South A Regional Ethics Committee
Ministry of Health
4th Floor, 250 Oxford Terrace
PO Box 3877
Christchurch
Phone (03) 372 3037
Fax (03) 372 1015



15 April 2008

Ms Franziska Gallrach
98a Perry Street
Papanui
Christchurch 8053

Dear Franziska Gallrach,

Early intervention and quality of life of people with dementia and their family-caregivers living in New Zealand

Investigator: Ms Franziska Gallrach
Locality: The Princess Margaret Hospital
Ethics ref: URA/07/06/044

Amendment:

To extend recruitment to include the whole Older Persons Health Service

Thank you for the above amendment, which has been considered by the Chairperson and Deputy Chairperson of the Upper South A Regional Ethics Committee, and approved under delegated authority.

Yours sincerely

Aleke Dierckx
Upper South A Ethics Committee Administrator
aleke_dierckx@moh.govt.nz

Upper South A Regional Ethics Committee
Ministry of Health
4th Floor, 250 Oxford Terrace
PO Box 3877
Christchurch
Phone (03) 372 3037
Fax (03) 372 1015

Appendix G: Invitation for study participation handed out by TPMH staff after diagnosis given

Health Sciences Centre
Tel: +64 3 3667 001 ext. 8362, Fax: + 64 3 364 2490
Email: healthsciences@canterbury.ac.nz

The Princess Margaret Hospital
Psychiatry of Old Age Academic Unit
Psychiatric Service for the Elderly



Invitation to join the study: “Quality of life of persons with dementia and their families”

Principal investigator:

- Franziska Gallrach, Ph.D.-student, Health Sciences Centre, University of Canterbury, Private Bag 4800, Christchurch
Phone: 03-364-2987 ext. 8362 at the University
Mobile: 0211286132
E-mail: FranziskaGallrach@web.de

Supervisors of the study:

- Dr Ray Kirk, Acting Director of the Health Sciences Centre, University of Canterbury
Phone: 03-364-3108
- Prof. Andrew Hornblow, Adjunct Professor Health Sciences Centre, University of Canterbury

Clinical advisors:

- Dr Matthew Croucher, Consultant Old Age Psychiatrist, Clinical Senior Lecturer, University of Otago; Psychiatry of Old Age Academic Unit at The Princess Margaret Hospital
- Dr Brian Deavoll, Consultant Psychiatrist, Psychiatric Service for the Elderly at The Princess Margaret Hospital

- You have been diagnosed as having dementia, which causes damage to brain cells and progressive memory loss.
- Living with dementia may not be easy and you may need a lot of support from your family, community, and health professionals.
- This study is student research. It is carried out by a Ph.D.-student to fulfil the requirements for the degree of Doctor of Philosophy in Health Sciences at the University of Canterbury.
- This study will include five questionnaires for you and four questionnaires for the person that takes care of you. It will take approximately two hours in total to fill in all questionnaires.
- You and your caregiver will be asked to complete all questionnaires again one year after the first time.
- The person who takes care of you will also be asked to take notes in a diary every week for one year. This will be information regarding the costs of caring for a person with dementia.
- By taking part in this study you will help us to detect the factors that influence your and your caregiver's quality of life the most. We hope to find ways to help you and your caregiver have a better quality of life.
- You do not have to take part in the research if you prefer not to.
- You may withdraw from the research project at any time.

Please take your time to read this information sheet carefully.

A week after you receive this information sheet the researcher, Miss Franziska Gallrach, will contact you and she will ask you whether you would like to participate or not, or if you would like to meet her for more explanation of the study. If you decide to participate, we will be very grateful for the valuable contribution you will be making to the research project. Its aim is to better understand what kind of support a person with dementia (PWD) and his/her family need. If you decide not to participate, there will be no disadvantage to you or your treatment or support plan, and we thank you for considering our request.

1. What is the aim of this study?

We aim to investigate how educational and/or supportive interventions impact on the well-being of people with dementia, and their families. We also aim to gain understanding of which of these interventions can reduce dementia-related direct and indirect costs, and which interventions are the most cost-effective.

2. Who can participate?

People can enter the study if they have been diagnosed with Alzheimer's disease and/or an Alzheimer's disease related dementia, such as vascular dementia, within the last three months. You will have been referred to this study through your memory specialist at The Princess Margaret Hospital. Entry into the study does not require any extra tests beyond the diagnosis process at The Princess Margaret Hospital.

3. How many participants will be involved?

100 persons with dementia and their families who are willing to participate in this study

4. What is your participation?

Your participation is voluntary and you are free to withdraw from the study at anytime without having to give a reason. There will be no disadvantage to you.

Your name and personal details are strictly confidential and will not be mentioned in the final report.

If you decide to participate, you and the person that cares for you (for example your wife, husband, or child) will be asked to sign a consent form when you are interviewed to confirm your and his/her willingness to be involved. Both of you will be given a copy of the consent form.

- The first interview will take one and a half hours (details of the interview are explained in point 7).
- A second interview, 12 months later, will be scheduled with you and your caregiver to see if there are any changes since the last interview. This will take another one and a half hours.
- The person who takes care of you will also be asked to take notes in a diary for one year.

5. Where will the interviews be conducted?

The interviews will be conducted at an appropriate private place. You can decide where the interviews will be conducted for example:

- At the University of Canterbury
- At your home
- At another place of your choice.

6. When and how will the interviews be conducted?

The study will involve one individual meeting between August 2007 and July 2008 (depending on when you received your diagnosis), and one further meeting twelve months later. We will compare your answers from the beginning of the study with the ones you give one year later to see if there are any changes during this year.

You and the person who takes care for you will be interviewed separately. You may need to arrange alternative care during this time.

7. What questions will you be asked?

During the first meeting:

- You will be asked questions about your health and well-being. There are no right or wrong answers. We are looking to record your experiences. This should take 20 to 30 minutes maximum to answer.
- Your caregiver will be asked the same questions about his/her health and well-being, and in addition some questions about you, about expenditures related to your memory difficulties, and how he/she feels at the moment. This will take about one hour.
- All data will be absolute confidential.
- Your caregiver will receive a diary where he/she will record for one year the services you use and some of your expenditures that you have because of your illness. Again, this data will be kept in absolute confidence. Under no circumstances the researcher is

interested in your wealth or otherwise. This could be done once per week and might take approximately 30 minutes.

- Your caregiver will also receive 12 prepaid envelopes which he/she can use to send the diaries back to us every month. Caregivers will automatically be reminded by telephone to fill in their diaries. Software, developed by TeleMessenger Solutions Limited (a software company from Christchurch), will be used for this purpose. This automatic phone call also allows caregivers to leave a message for the researcher if they have any questions or problems.

During the second meeting, 12 months later:

- We will assess how far your illness has progressed.
- You will be asked the same questions about your health and well-being like one year ago. This will take 20-30 minutes.
- Your carer will be also asked the same questions again. This can take up to one hour.
- You can decide if you prefer to have the assessment and the interview all in one meeting (approximately three hours) or if you prefer to have two separate meetings (each meeting approximately one and a half hours).
- At any point you can interrupt the interview if you feel unwell and we can schedule another time to continue.

After the second meeting, 12 months later:

- With your consent, we would like to confirm some of the information that you and your caregiver would have given us during the interviews and in the diaries about your use of support services and their costs with the Nurse Maude Association (if you are one of their clients).

8. What will happen to the information?

Every participant will be identified with a study number (no names will be used). All the information will be kept at the Health Sciences Centre at the University of Canterbury. Only the researcher and two supervisors will have access to it to enable your answers to be analysed. Documents will be stored in a locked cabinet in the researcher's office at the Health Sciences Centre. Data will be stored on the researcher's password protected computer. At the end of the study the data will be kept securely by the Health Sciences Centre for 10 years and after the data will be destroyed.

9. What are the risks and the benefits of the study?

There is no risk to you as a participant, other than possible sadness about sharing difficult experiences. If there are some questions you do not want to answer, you are free not to answer. The benefit of the study is that your opinion on what has helped you and your family to cope with dementia could be useful to better address other dementia patients' needs in New Zealand.

10. What if there is a problem?

If a medical problem either with you or with the person who takes care of you or any other problem emerges during the course of the interview, the researcher will offer to arrange appropriate assistance or contact the relevant person if needed.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent Health and Disability Advocate, as follows: South Island 0800 377 766 Free Fax (NZ wide) 0800 2787 7678 (0800 2 SUPPORT). E-mail: advocacy@hdc.org.nz

11. What will happen to the results of the study?

It is expected that the final writing of the research will be completed by the end of 2009. You will receive a copy of the summary of the final report if you wish.

Dr. Brian Deavoll, Director of the memory clinic at The Princess Margaret Hospital and Alzheimer's Canterbury will receive a full copy of the final report.

12. Who pays for the research?

The study is financed by the University of Canterbury.

13. What kind of compensation will you receive?

If you decide to participate, your travel costs (if any) to the place you have chosen as most convenient for the interview will be reimbursed.

14. Who has reviewed the study?

This study has received ethical approval from the Upper South A Regional Ethics Committee.

15. Where can you receive more information?

You can request more detailed information from the principal researcher – Miss Franziska Gallrach- 03-3 667 001 extension 8362 at the University or at any time at 0211286132.

E-mail: FranziskaGallrach@web.de

Thank you for considering taking part in this study and for taking time to read this paper!

Appendix H: Invitation for study participation published in Alzheimers Canterbury newsletter

Study on Quality of Life and Dementia

During the last 10 years quality of life has become an important dimension of dementia therapeutic research. We all know how important it is for the person with dementia as well as for the carer not only to get medical treatment but also to experience social, psychological and educational support for example through Alzheimers Canterbury.

The University of Canterbury together with Princess Margaret Hospital and Alzheimers Canterbury plans a study on quality of life and dementia. The aim of this study is to find out how educational and psychosocial interventions can influence the quality of life of the person affected by dementia and of the family-caregiver. To answer this question the university will conduct questionnaires with 100 persons who have been recently diagnosed with dementia and their carers. The same questionnaires – which take about two hours – will be looked at again after 1 year. In the meantime the participants will monthly record the support they received in a diary.

The University of Canterbury is now looking for people who would like to participate in this study. If you are interested please contact:

Franziska Gallrach
PhD-Candidate in Health Sciences
Health Sciences Centre
University of Canterbury, Christchurch
Telephone: 3 525 250 or 3 667 001 ext. 8362
E-Mail: FranziskaGallrach@web.de

Appendix I: Letter from the Clinical Director of Older Persons Health to introduce the study to colleagues in order to identify patients who were diagnosed with dementia but not referred to TPMH-Older Persons Health

Canterbury

District Health Board

Te Poari Hauora o Waitaha

**Older Persons Health
Canterbury District Health Board**

Wednesday 7th May 2008

To Whom It May Concern

Dear Colleague,

You have been approached by Franziska Gallrach, a PhD student with the University of Canterbury, for assistance to identify whether or not one of the people you have had contact with through Older Persons Health might be eligible to enter a research study. Ms Gallrach is enrolling people recently diagnosed with dementia (of any type and severity) who live at home, and their primary carer. The purposes of the study are to find out what supports and interventions from primary and secondary care are helpful for enhancing quality of life, and what these interventions cost. I anticipate that the results will be valuable to assist us to provide a better service to this important group of people.

Ms Gallrach will identify potential participants from SAP / Healthlinks data. She will find the key contact or case manager within the service to double check the eligibility of the potential participant, and then check with you which carer to approach and ensure that there are no extra sensitivities that need to be respected. Her approach will follow a no-obligation protocol as approved by the Ethics Committee and OPH and will not require any further input from you.

This study has been approved by the regional Ethics Committee and by myself. Thank you for assisting Ms Gallrach in any way you can.

Yours sincerely,


**Dr Jeff Kirwan
Clinical Director
Older Persons Health.**

Appendix J: Sample email sent to registrars of PWDs identified through discharge letters from the CDHB database

Dear Dr ...,

My name is Franziska Gallrach. I am a Ph.D. student with the University of Canterbury. I am conducting a study on quality of life in dementia. So far potential participants have been drawn from the Psychiatry Services for the Elderly alone. Recently I obtained ethical approval to also identify potential participants from the whole Older Persons Health service. In this process I went through all OPH discharge letters from June until now and identified the following patients as potential participants:

1. CDHB identifier 1
2. CDHB identifier 2
3. CDGH identifier 3.

It is not always clear if patients have been diagnosed with dementia (and have been told this diagnosis) and how long ago a diagnosis was made.

My inclusion criteria are:

1. patient diagnosed recently (within the last 6 months) with mild, moderate or severe dementia
2. patient must have an informal caregiver
3. patient must still be living at home or assisted living facility, e.g. Kate Sheppard villas (not residential care).

For further explanation please see the attached letter from Dr Jeff Kirwan. It would be of great help if you might be able to tell me if I am able to approach these patients and their families from your point of view, and if they actually meet the inclusion criteria. I am most grateful for your assistance.

Yours sincerely,

Franziska Gallrach

Ph.D.-Candidate (Health Sciences), MA, BA Health Sciences Centre
University of Canterbury Private Bag 4800 Christchurch, NEW ZEALAND
Telephone: +64 (0)3-364 2987 ext.8362
Mobile: 021 128 6132
Email: FranziskaGallrach@web.de

Appendix K: Consent forms for patients, caregivers and informants

• Participants' Consent Forms

Health Sciences Centre

Tel: +64 3 364 2987, Fax: + 64 3 364 2490
Email: healthsciences@canterbury.ac.nz



PATIENT CONSENT FORM

For the study

“Early Intervention and Quality of Life of People with
Dementia and their Caregivers”

Please tick to confirm.

- I have read and understand the information sheet dated 18 July 2007 for the above research study.
- I have had the opportunity to ask questions about the research study, and to discuss it with family and friends and I have had time to consider whether to take part.
- I understand the purpose of the research study, and how I will be involved.
- I understand that taking part of the study is voluntary (my choice) and I understand that I may withdraw from it, at any time and for any reason.
- I understand that my participation in this study is confidential and that my name and personal details will not be included in the report.
- I agree that information about my diagnosis will be provided, in confidence, by my doctor from The Princess Margaret Hospital.
- I agree that the Nurse Maude Association might be contacted to confirm some of the information I have given.
- I know who to contact should I have any questions whatsoever about the study or my participation in the study.
- I understand that I will be contacted again one year after the first interview for a second interview.
- I wish to receive a summary of the study's results: YES / NO.

I _____ (please print full name)

consent to take part in the above research study.

Signed [Participant] _____ Date _____

Project explained by: _____ Date _____

This study is being conducted by Miss Franziska Gallrach, PhD student (Health Sciences) University of Canterbury, Christchurch.
You can contact Franziska at the university: 364 2987 extension: 8362, or 0211286132 if you have any question or wish to discuss your participation.

E-Mail address: FranziskaGallrach@web.de

Supervision: This project is being undertaken under University of Canterbury Health Sciences Centre supervision.

- Prof Andrew Hornblow, Health Sciences Centre. (Ph. 364 7628)
- Dr Ray Kirk, Acting Director of the Health Sciences Centre. (Ph. 364 3108)

Health Sciences Centre

Tel: +64 3 364 2987, Fax: + 64 3 364 2490
Email: healthsciences@canterbury.ac.nz



CAREGIVER CONSENT FORM

For the study

“Early Intervention and Quality of Life of People with
Dementia and their Caregivers”

Please tick to confirm.

- I have read and understand the information sheet dated 18 July 2007 for the above research study.
- I have had the opportunity to ask questions about the research study, and to discuss it with family and friends and I have had time to consider whether to take part.
- I understand the purpose of the research study, and how I will be involved.
- I understand that taking part of the study is voluntary (my choice) and I understand that I may withdraw from it, at any time and for any reason.
- I understand that my participation in this study is confidential and that my name and personal details will not be included in the report.
- I agree to provide information about the patient's progress and how his/her disease affects me.
- I agree that information about the patient's diagnosis will be provided, in confidence, by his/her doctor from The Princess Margaret Hospital.
- I agree that the Nurse Maude Association might be contacted to confirm some of the information I have given.
- I know who to contact should I have any questions whatsoever about the study or my participation in the study.
- I understand that I will be contacted again one year after the first interview for a second interview. I also understand that I am asked to record some information in a diary over the 12 month period.
- I wish to receive a summary of the study's results: YES / NO.

I _____ (please print full name)

consent to take part in the above research study.

Signed [Participant] _____ Date _____

Project explained by: _____ Date _____

This study is being conducted by Miss Franziska Gallrach, PhD student (Health Sciences) University of Canterbury, Christchurch.
You can contact Franziska at the university: 364 2987 extension: 8362, or 0211286132 if you have any question or wish to discuss your participation.

E-Mail address: FranziskaGallrach@web.de

Supervision: This project is being undertaken under University of Canterbury Health Sciences Centre supervision.

- Prof Andrew Hornblow, Health Sciences Centre. (Ph. 364 7628)
- Dr Ray Kirk, Acting Director of the Health Sciences Centre. (Ph. 364 3108)

Health Sciences Centre

Tel: +64 3 364 2987, Fax: + 64 3 364 2490
 Email: healthsciences@canterbury.ac.nz



CAREGIVER PROXY CONSENT FORM

For the study

“Early Intervention and Quality of Life of People with
 Dementia and their Caregivers”

Please tick to confirm.

- I have read and understand the information sheet dated 18 July 2007 for the above research study.
- I have had the opportunity to ask questions about the research study, and to discuss it with family and friends and I have had time to consider whether to take part.
- I understand the purpose of the research study, and how I will be involved.
- I understand that taking part of the study is voluntary (my choice) and I understand that I may withdraw from it, at any time and for any reason.
- I understand that my participation in this study is confidential and that my name and personal details will not be included in the report.
- I agree to provide information about the patient's progress and how his/her disease affects me.
- I agree that information about the patient's diagnosis will be provided, in confidence, by his/her doctor from The Princess Margaret Hospital.
- I agree that the Nurse Maude Association might be contacted to confirm some of the information I have given.
- I know who to contact should I have any questions whatsoever about the study or my participation in the study.
- I understand that I will be contacted again one year after the first interview for a second interview. I also understand that I am asked to record some information in a diary over the 12 month period.
- I wish to receive a summary of the study's results: YES / NO.

I _____ (please print full name)

consent for the patient _____ (please print full name)

to take part in the above research study.

Signed [Participant] _____ Date _____

Project explained by: _____ Date _____

This study is being conducted by Miss Franziska Gallrach, PhD student (Health Sciences) University of Canterbury, Christchurch.

You can contact Franziska at the university: 364 2987 extension: 8362, or 0211286132 if you have any question or wish to discuss your participation.

E-Mail address: FranziskaGallrach@web.de

Supervision: This project is being undertaken under University of Canterbury Health Sciences Centre supervision.

- Prof Andrew Homblow, Health Sciences Centre. (Ph. 364 7628)
 - Dr Ray Kirk, Acting Director of the Health Sciences Centre. (Ph. 364 3108)
-

Appendix L: Questionnaires and example diary sheets

Participant's number: ____
 Date: ____/____/____
 Diagnosis: _____
 3MS: ____/100

Health Sciences Centre
 Tel: +64 3 3667 001 ext. 8362
 Email:
 healthsciences@canterbury.ac.nz



CAREGIVER's AND PWD's DETAILS

Thank you for helping our research into dementia by taking part in the QoL study. Please provide the following details about yourselves (if you have any difficulties please ask).

1. Your Name : _____

2. Your Address: _____

Postcode/ Suburb: _____ Telephone: _____

3. PWD's Name : _____

4. PWD's Address (if different from yours): _____

Postcode/ Suburb: _____ Telephone (if different): _____

5. Who lives with the PWD? _____

6. What is your age? _____ and sex? Male ☐ Female ☐

7. What is your ethnicity?
- ☐ New Zealand European
 - ☐ Māori
 - ☐ Samoan
 - ☐ Cook Island Māori
 - ☐ Tongan
 - ☐ Niuean
 - ☐ Chinese
 - ☐ Indian
 - ☐ Other (such as Dutch, Japanese, Tokelauan). Please state: _____

8. What is your relationship to the PWD? Husband/Wife ☐ Son/Daughter ☐
 Other ☐ Please specify: _____

9. What is the PWD's age? _____ and sex? Male ☐ Female ☐

10. What is the PWD's ethnicity?
- ☐ New Zealand European
 - ☐ Māori
 - ☐ Samoan
 - ☐ Cook Island Māori
 - ☐ Tongan
 - ☐ Niuean
 - ☐ Chinese
 - ☐ Indian
 - ☐ Other (such as Dutch, Japanese, Tokelauan). Please state: _____

11. Did your education continue after the minimum school leaving age? Yes ☐ No ☐

12. Do you have a degree or equivalent professional qualification? Yes ☐ No ☐

13. What is, or was, your occupation? _____

14. Are you currently in paid employment? Yes ☐ No ☐

If YES, please say how many days could you not work because of your role as a carer for a person with dementia in the last two weeks: _____ days.

14. Did the PWD's education continue after the minimum school leaving age? Yes ☐ No ☐

15. Does the PWD have a degree or equivalent professional qualification? Yes ☐ No ☐

16. What is, or was, the PWD's occupation? _____

17. Income:

• Is your joint income/ pension: NZ\$ < 25 000,- NZ\$ 25 000 - 50 000,- NZ\$ > 50 000,-

• Are you a holder of the Community Service Card? Yes ☐ No ☐

• Is the PWD a holder of the Community Service Card? Yes ☐ No ☐

YOUR HEALTH

5. Have you had to stay overnight in hospital over the last three months? NO ☐ YES ☐
If YES, please give details:

Which hospital?	Reason stayed	Number of nights

6. Have you seen a GP and/or hospital doctor for your health in the last three months?

NO ☐ YES, GP ☐ YES, hospital doctor ☐

If YES, please give details:

Who did you see?	Reason seen	Number of visits

7. Medicines for you

List any mental health medicines, which you bought for yourself from your chemist (if any) in the last three months:

Date: ____/____/____

Thank you!

Comorbidities PWD

Besides any memory or cognitive problems you may have, is your quality of life significantly worsened by any of these physical or mental health problem(s) at the moment?

If YES: How severe is the impact upon your quality of life?

Health problems	Normal, not at all (1)	Mild (2)	Moderate (3)	Marked (4)	Quite severe (5)
Heart attack					
Heart failure					
Stroke					
Angina					
Emphysema/ asthma					
Shortness of breath					
Headache					
Impaired vision					
Impaired hearing					
Dizziness					
Parkinsonism					
Falls					
Skin problems					
Blood problems					
Diabetes					

Health problems	Normal, not at all (1)	Mild (2)	Moderate (3)	Marked (4)	Quite severe (5)
Broken bones					
Arthritis					
Other joint problems					
Nausea					
Bowel problems					
Incontinence					
Kidney failures					
Thyroid disease					
Surgery					
Cancer					
Other causes of chronic pain (please name)					
Any other cause (please name)					

Comorbidities Informant

Besides any memory or cognitive problems **the person you take care for** may have, is **his/her** quality of life significantly worsened by any of these physical or mental health problem(s) at the moment?

If YES: How severe is the impact upon **his/her** quality of life?

Health problems	Normal, not at all (1)	Mild (2)	Moderate (3)	Marked (4)	Quite severe (5)
Heart attack					
Heart failure					
Stroke					
Angina					
Emphysema/ asthma					
Shortness of breath					
Headache					
Impaired vision					
Impaired hearing					
Dizziness					
Parkinsonism					
Falls					
Skin problems					
Blood problems					
Diabetes					

Health problems	Normal, not at all (1)	Mild (2)	Moderate (3)	Marked (4)	Quite severe (5)
Broken bones					
Arthritis					
Other joint problems					
Nausea					
Bowel problems					
Incontinence					
Kidney failures					
Thyroid disease					
Surgery					
Cancer					
Other causes of chronic pain (please name)					
Any other cause (please name)					

Comorbidities Caregiver

Is **your** quality of life significantly worsened by any of these physical or mental health problem(s) at the moment?

If YES: How severe is the impact upon **your** quality of life?

Health problems	Normal, not at all (1)	Mild (2)	Moderate (3)	Marked (4)	Quite severe (5)
Heart attack					
Heart failure					
Stroke					
Angina					
Emphysema/ asthma					
Shortness of breath					
Headache					
Impaired vision					
Impaired hearing					
Dizziness					
Parkinsonism					
Falls					
Skin problems					
Blood problems					
Diabetes					

Health problems	Normal, not at all (1)	Mild (2)	Moderate (3)	Marked (4)	Quite severe (5)
Broken bones					
Arthritis					
Other joint problems					
Nausea					
Bowel problems					
Incontinence					
Kidney failures					
Thyroid disease					
Surgery					
Cancer					
Other causes of chronic pain (please name)					
Any other cause (please name)					

Quality of Life: AD

(Patient)

Patient's name: _____ Date: ____/____/____

Interviewer administer according to standard instructions.
Circle responses.

1. Physical health.	Poor	Fair	Good	Excellent
2. Energy.	Poor	Fair	Good	Excellent
3. Mood.	Poor	Fair	Good	Excellent
4. Living situation.	Poor	Fair	Good	Excellent
5. Memory.	Poor	Fair	Good	Excellent
6. Family.	Poor	Fair	Good	Excellent
7. Marriage.	Poor	Fair	Good	Excellent
8. Friends.	Poor	Fair	Good	Excellent
9. Self as a whole.	Poor	Fair	Good	Excellent
10. Ability to do chores around the house.	Poor	Fair	Good	Excellent
11. Ability to do things for fun.	Poor	Fair	Good	Excellent
12. Money.	Poor	Fair	Good	Excellent
13. Life as a whole.	Poor	Fair	Good	Excellent

Comments:

Quality of Life: AD

(Informant/ Caregiver)

Caregiver's name: _____ Date: ____/____/____

The following questions are about your relative's quality of life.

When you think about your relative's life, there are different aspects, some of which are listed below. Please think about each item, and rate your relative's current quality of life in each area using one of four words: poor, fair, good, or excellent. Please rate these items based on your relative's life at the present time (e.g. within the past few weeks). If you have questions about any item, please ask the person who gave you this form for assistance.

Circle your responses.

1. Physical health.	Poor	Fair	Good	Excellent
2. Energy.	Poor	Fair	Good	Excellent
3. Mood.	Poor	Fair	Good	Excellent
4. Living situation.	Poor	Fair	Good	Excellent
5. Memory.	Poor	Fair	Good	Excellent
6. Family.	Poor	Fair	Good	Excellent
7. Marriage.	Poor	Fair	Good	Excellent
8. Friends.	Poor	Fair	Good	Excellent
9. Self as a whole.	Poor	Fair	Good	Excellent
10. Ability to do chores around the house.	Poor	Fair	Good	Excellent
11. Ability to do things for fun.	Poor	Fair	Good	Excellent
12. Money.	Poor	Fair	Good	Excellent
13. Life as a whole.	Poor	Fair	Good	Excellent

Comments:

Quality of Life: AD

(Caregiver)

Caregiver's name: _____ Date: ____/____/____

The following questions are about your own quality of life.

Please rate these items based on your own life at the present time (e.g. within the past few weeks). If you have questions about any item, please ask the person who gave you this form for assistance.

Circle your responses.

1. Physical health.	Poor	Fair	Good	Excellent
2. Energy.	Poor	Fair	Good	Excellent
3. Mood.	Poor	Fair	Good	Excellent
4. Living situation.	Poor	Fair	Good	Excellent
5. Memory.	Poor	Fair	Good	Excellent
6. Family.	Poor	Fair	Good	Excellent
7. Marriage.	Poor	Fair	Good	Excellent
8. Friends.	Poor	Fair	Good	Excellent
9. Self as a whole.	Poor	Fair	Good	Excellent
10. Ability to do chores around the house.	Poor	Fair	Good	Excellent
11. Ability to do things for fun.	Poor	Fair	Good	Excellent
12. Money.	Poor	Fair	Good	Excellent
13. Life as a whole.	Poor	Fair	Good	Excellent

Comments:

Cornell Scale for Depression in Dementia

Patient's/ Caregiver's name: _____ Date: ____/____/____

Scoring system

a = unable to evaluate 1 = mild or intermittent
0 = absent 2 = severe

A. Mood-Related Signs

1. Anxiety (anxious expression, ruminations, worrying)	a 0 1 2
2. Sadness (sad expression, sad voice, tearfulness)	a 0 1 2
3. Lack of reactivity to pleasant events	a 0 1 2
4. Irritability (easily annoyed, short tempered)	a 0 1 2
B. Behavioural Disturbance	
5. Agitation (restlessness, hand wringing, hair pulling)	a 0 1 2
6. Retardation. (slow movements, slow speech, slow reactions)	a 0 1 2

7. Multiple physical complaints (score 0 if GI symptoms only)	a 0 1 2
--	------------------------

8. Loss of interest – less involved in usual activities (score only if change occurred acutely, i.e., in less than 1 month)	a 0 1 2
--	------------------------

C. Physical Signs

9. Appetite Loss (eating less than usual)	a 0 1 2
--	------------------------

10. Weight loss (score 2 if greater than 5 lb in 1 month)	a 0 1 2
--	------------------------

11. Lack of energy (fatigues easily, unable to sustain activities – Score only if change occurred acutely, i.e., in less than 1 month)	a 0 1 2
--	------------------------

D. Cyclic Functions

12. Diurnal variation of mood (symptoms worse in the morning)	a 0 1 2
--	------------------------

13. Difficulty falling asleep (later than usual for his individual)	a 0 1 2
--	------------------------

14. Multiple awakenings during sleep	a 0 1 2
--------------------------------------	------------------------

15. Early morning awakening (earlier than usual for his individual)	a 0 1 2
--	------------------------

E. Ideational Disturbance

16. Suicide (feels life is not worth living, has suicidal wishes, or makes suicide attempt)	a 0 1 2
17. Poor self-esteem (self-blame, self-depreciation, feelings of failure)	a 0 1 2
18. Pessimism (anticipation of the worst)	a 0 1 2
19. Mood-congruent delusions (delusions of poverty, illness, or loss)	a 0 1 2

Sum (Items1-19):

--	--

Modified Mini-Mental State Examination (3MS)

Name _____ Date ____/____/____ AGE ____ 3MS ____ MMSE ____	
yrs. 100 30	
3MS MMSE	
5	PLACE & DATE OF BIRTH: Place: Town _____, State _____ Time: Year _____, Mo. _____, Date _____
3	REGISTRATION # ____: (No. Presentations ____) #1: Shirt _____, Brown _____, Honesty _____ #2: Shoes _____, Black _____, Modesty _____ #3: Socks _____, Blue _____, Charity _____
7	MENTAL REVERSAL (Coach fwd. once if needed) 5 to 1 (Can ____ Can't ____ count 1-5) Accurate 2 1 or 2 errors/misses 1 3 or more errors/misses 0
	DLROW (Can ____ Can't ____ spell WORLD) 0 1 2 3 4 5
9	FIRST RECALL Spontaneous recall 3 After "Something to wear" 2 After "SHOES, SHIRT, SOCKS" 1 Still does not know 0
	Spontaneous recall 3 After "A color" 2 After "BLUE, BLACK, BROWN" 1 Still does not know 0
	Spontaneous recall 3 After "A good personal quality" 2 After "HONESTY, CHARITY, MODESTY" 1 Still does not know 0
15	TEMPORAL ORIENTATION Year Accurate 8 Missed by 1 yr. 4 Missed by 2 - 5 yrs. 2 Missed by > 5 yrs. 0 Month Accurate or within 5 days 2 Missed by 6 days to 1 mo. 1 Missed by > 1 mo. 0 Date (of the month) Accurate 3 Missed 1-2 days 2 Missed 3-5 days 1 Missed > 5 days 0 Day (of the week) Accurate 1 Inaccurate 0 Season (changes ~ 20th of M J S D) Accurate (within 30 days) 1 Inaccurate 0
5	SPATIAL ORIENTATION State 0 2 County 0 1 City/Town 0 1 Store/Hospital/Clinic/Home? 0 1
5	NAMING (MMSE: Pencil ____, Watch ____) Forehead ____, Chin ____, Shoulder ____, Elbow ____, Knuckle ____
10	FOUR-LEGGED ANIMALS (30 sec.) SIMILARITIES (Coach with Orange-Banana) Arm-Leg (Teach if score <2) Body parts; limbs; extremities 2 Other correct answer 1 Incorrect; tells difference; DK 0 Laughing-Crying Feelings; emotions 2 Other correct answer 1 Incorrect; tells difference; DK 0 Eating-Sleeping Essential for life 2 Other correct answer 1 Incorrect; tells difference; DK 0
5	REPETITION "HE WOULD LIKE TO GO HOME." 2 1 or 2 missed/wrong words 1 > 3 missed/wrong words 0 "NO IFS ____ ANDS ____ OR BUTS ____"
3	READ AND OBEY "CLOSE YOUR EYES" Obey without prompting 3 Obey after prompting 2 Reads only 1 Neither reads nor obeys 0
5	WRITING (1 minute) (HE) WOULD LIKE TO GO HOME
10	COPYING 2 PENTAGONS (1 minute) Each Ptn.: 5 approx. equal sides 4 4 5 but unequal (>2:1) sides 3 3 Other enclosed figure 2 2 2 or more lines 1 1 less than 2 lines 0 0 Intersection: 4 corners 2 Not 4-cornered enclosure 1 No intersection 0
3	THREE-STAGE COMMAND (Finish cmds first) TAKE THIS PAPER WITH YOUR L/R FOLD IT IN HALF, AND HAND IT BACK TO ME
9	SECOND REGALL (SHOES, SHIRT, SOCKS) 0 1 2 3 (BLUE, BLACK, BROWN) 0 1 2 3 (HONESTY, CHARITY, MODESTY) 0 1 2 3

Caregiver's name: _____ Date: ____/____/____

NEUROPSYCHIATRIC INVENTORY (NPI)

DELUSIONS

1. Does the patient have beliefs that you know are not true?
For example, insisting that people are trying to harm him/her.
Has he/she said that family members are not who they say they are or that the house is not their home?
I'm not asking about mere suspiciousness; I am interested if the patient is convinced that these things are happening to him/her.

No ☐ N/A ☐
Yes ☐ If yes rate frequency → Occasionally ☐ Often ☐
and severity ↓ Frequently ☐ Very Frequently ☐

Mild ☐ delusions present but seem harmless and produce little distress in the patient
Moderate ☐ delusions are distressing and disruptive
Marked ☐ delusions are very disruptive and are a major source of behavioural disruption. (If PRN medications are prescribed, their use signals that the delusions are of marked severity).

HALLUCINATIONS

2. Does the patient have hallucinations such as false visions or voices?
Does he/she seem to see, hear or experience things that are not present?
By this question we do not mean just mistaken beliefs such as stating that someone who has died is still alive; rather we are asking if the patient actually has abnormal experiences of sounds, or visions.

No ☐ N/A ☐
Yes ☐ If yes rate frequency → Occasionally ☐ Often ☐
and severity ↓ Frequently ☐ Very Frequently ☐

Mild ☐ hallucinations are present but harmless and cause little distress for the patient
Moderate ☐ hallucinations are distressing and are disruptive to the patient
Marked ☐ hallucinations are very disruptive and are a major source of behavioural disturbance. PRN medications may be required to control them

AGITATION/AGGRESSION

3. Does the patient have periods when he/she refuses to cooperate or won't let people help him/her?
Is he/she hard to handle?

No ☐ N/A ☐
Yes ☐ If yes rate frequency → Occasionally ☐ Often ☐
and severity ↓ Frequently ☐ Very Frequently ☐

Mild ☐ behaviour disruptive but can be managed with redirection or reassurance.
Moderate ☐ behaviours disruptive and difficult to redirect or control.
Marked ☐ behaviour is very disruptive and a major source of difficulty. There may be a threat of personal harm. Medications are often required.

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DEPRESSION/DYSPHORIA

4. Does the patient seem sad or depressed?
Does he/she say that he/she feels sad or depressed?

No ☐ N/A ☐
Yes ☐ If yes rate frequency → Occasionally ☐ Often ☐
and severity ↓ Frequently ☐ Very Frequently ☐

Mild ☐ depression is distressing but usually responds to redirection or reassurance
Moderate ☐ depression is distressing, depressive symptoms are spontaneously voiced by the patient and difficult to alleviate
Marked ☐ depression is very distressing and a major source of suffering for the patient

ANXIETY

5. Is the patient very nervous, worried, or frightened for no apparent reason?
Does he/she seem very tense or fidgety?
Is the patient afraid to be apart from you?

No ☐ N/A ☐
Yes ☐ If yes rate frequency → Occasionally ☐ Often ☐
and severity ↓ Frequently ☐ Very Frequently ☐

Mild ☐ anxiety is distressing but usually responds to redirection or reassurance
Moderate ☐ anxiety is distressing, anxiety symptoms are spontaneously voiced by the patient and difficult to alleviate
Marked ☐ anxiety is very distressing and a major source of suffering for the patient.

ELATION/EUPHORIA

6. Does the patient seem too cheerful or too happy for no reason?
I don't mean the normal happiness that comes from seeing friends, receiving presents or spending time with family members. I am asking if the patient has a persistent and abnormally good mood or finds humour where others do not.

No ☐ N/A ☐
Yes ☐ If yes rate frequency → Occasionally ☐ Often ☐
and severity ↓ Frequently ☐ Very Frequently ☐

Mild ☐ elation is notable to friends and family but is not disruptive
Moderate ☐ elation is notably abnormal
Marked ☐ elation is very pronounced, patient is euphoric and finds nearly everything to be humorous

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APATHY/INDIFFERENCE

7. *Has the patient lost interest in the world around him/her?*
Has he/she lost interest in doing things or lack motivation for starting new activities?
Is he/she more difficult to engage in conversation or in doing chores?
Is the patient apathetic or indifferent?

No ☐ N/A ☐
Yes ☐ If yes rate frequency → Occasionally ☐ Often ☐
and severity ↓ Frequently ☐ Very Frequently ☐

- Mild ☐ apathy is notable but produces little interference with daily routines; only mildly different from patient's usual behaviour; patient responds to suggestions to engage in activities.
Moderate ☐ apathy is very evident; may be overcome by the caregiver with coaxing and encouragement; responds spontaneously only to powerful events such as visits from close relatives or family members.
Marked ☐ apathy is very evident and usually fails to respond to any encouragement or external events.

DISINHIBITION

8. *Does the patient seem to act impulsively without thinking?*
Does he/she do or say things that are not usually done or said in public?
Does he/she do things that are embarrassing to you or others?

No ☐ N/A ☐
Yes ☐ If yes rate frequency → Occasionally ☐ Often ☐
and severity ↓ Frequently ☐ Very Frequently ☐

- Mild ☐ disinhibition is notable but usually responds to redirection or guidance.
Moderate ☐ disinhibition is very evident and difficult to overcome by the caregiver.
Marked ☐ disinhibition usually fails to respond to any intervention by the caregiver, and is a source of embarrassment or social distress.

IRRITABILITY/LABILITY

9. *Does the patient get irritated and easily disturbed?*
Are his/her moods very changeable? Is he/she abnormally impatient?
We do not mean frustration over memory loss or inability to perform usual tasks; we are interested to know if the patient has abnormal irritability, impatience, or rapid emotional changes different from his/her usual self.

No ☐ N/A ☐
Yes ☐ If yes rate frequency → Occasionally ☐ Often ☐
and severity ↓ Frequently ☐ Very Frequently ☐

- Mild ☐ irritability or lability is notable but usually responds to redirection and reassurance.
Moderate ☐ irritability and lability are very evident and difficult to overcome by the caregiver.
Marked ☐ irritability and lability are very evident; they usually fail to respond to any intervention by the caregiver, and they are a major source of distress.

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ABERRANT MOTOR BEHAVIOUR

10. *Does the patient pace, do things over and over such as opening closets or drawers, or repeatedly pick at things or wind strings or threads?*

No ☐ N/A ☐
Yes ☐ If yes rate frequency → Occasionally ☐ Often ☐
and severity ↓ Frequently ☐ Very Frequently ☐

- Mild ☐ abnormal motor activity is notable but produces little interference with routines.
Moderate ☐ abnormal motor activity is very evident; can be overcome by the caregiver.
Marked ☐ abnormal motor activity is very evident; it usually fails to respond to any intervention by the caregiver and is a major source of distress.

SLEEP

11. *Does the patient have difficulty sleeping?* (do not count as present if the patient simply gets up once or twice per night only to go to the bathroom and falls back asleep immediately)
Is he/she up at night?
Does he/she wander at night, get dressed, or disturb your sleep?

No ☐ N/A ☐
Yes ☐ If yes rate frequency → Occasionally ☐ Often ☐
and severity ↓ Frequently ☐ Very Frequently ☐

- Mild ☐ night-time behaviours occur but they are not particularly disruptive.
Moderate ☐ night-time behaviours occur and disturb the patient and the sleep of the caregiver; more than one type of night-time behaviour may be present.
Marked ☐ night-time behaviours occur; several types of night-time behaviour may be present; the patient is very distressed during the night and the caregiver's sleep is markedly disturbed.

APETITE/EATING DISORDERS

12. *Has he/she had any change in appetite, weight, or eating habits* (count as not applicable (N/A) if the patient is incapacitated and has to be fed)?
Has there been any change in type of food he/she prefers?

No ☐ N/A ☐
Yes ☐ If yes rate frequency → Occasionally ☐ Often ☐
N/A ☐ and severity ↓ Frequently ☐ Very Frequently ☐

- Mild ☐ changes in appetite or eating are present but have not led to changes in weight and are not disturbing.
Moderate ☐ changes in appetite or eating are present and cause minor fluctuation in weight.
Marked ☐ obvious changes in appetite or eating are present and cause fluctuations in weight, are embarrassing, or otherwise disturb the patient.

Signature of person administering NPI: Date:

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Bristol Activities of Daily Living Scale

Caregiver's name: _____ Date: ____/____/____

This questionnaire is designed to reveal the everyday ability of people who have memory difficulties of one form or another.

For each activity (No. 1 - 20), statements a - e refer to a different level of ability.

Thinking of the last 2 weeks, tick the box that represents your relative's/friend's AVERAGE ability. (If in doubt about which box to tick, choose the level of ability which represents their *average* performance over the last 2 Weeks. Tick 'Not applicable' if your relative never did that activity when they were well).

1. PREPARING FOOD	<input type="checkbox"/>	a) Selects and prepares food as required
	<input type="checkbox"/>	b) Able to prepare food if ingredients set out
	<input type="checkbox"/>	c) Can prepare food if prompted step by step
	<input type="checkbox"/>	d) Unable to prepare food even with prompting and supervision
	<input type="checkbox"/>	e) Not applicable
2. EATING	<input type="checkbox"/>	a) Eats appropriately using correct cutlery
	<input type="checkbox"/>	b) Eats appropriately if food made manageable and /or uses spoon
	<input type="checkbox"/>	c) Uses fingers to eat food
	<input type="checkbox"/>	d) Needs to be fed
	<input type="checkbox"/>	e) Not applicable
3. PREPARING DRINK	<input type="checkbox"/>	a) Selects and prepares drinks as required
	<input type="checkbox"/>	b) Can prepare drinks if ingredients left available
	<input type="checkbox"/>	c) Can prepare drinks if prompted step by step
	<input type="checkbox"/>	d) Unable to make a drink even with prompting and supervision
	<input type="checkbox"/>	e) Not applicable
4. DRINKING	<input type="checkbox"/>	a) Drinks appropriately
	<input type="checkbox"/>	b) Drinks appropriately with aids, beaker/straw etc.
	<input type="checkbox"/>	c) Does not drink appropriately even with aids but attempts to
	<input type="checkbox"/>	d) Has to have drinks administered (fed)
	<input type="checkbox"/>	e) Not applicable
5. DRESSING	<input type="checkbox"/>	a) Selects appropriate clothing and dresses self
	<input type="checkbox"/>	b) Puts clothes on in wrong order and /or back to front and /or dirty clothing
	<input type="checkbox"/>	c) Unable to dress self but moves limbs to assist
	<input type="checkbox"/>	d) Unable to assist and requires total dressing
	<input type="checkbox"/>	e) Not applicable

6. HYGIENE	<input type="checkbox"/>	a) Washes regularly and independently
	<input type="checkbox"/>	b) Can wash self if given soap, flannel, towel, etc.
	<input type="checkbox"/>	c) Can wash self if prompted and supervised
	<input type="checkbox"/>	d) Unable to wash self and needs full assistance
	<input type="checkbox"/>	e) Not applicable
7. TEETH	<input type="checkbox"/>	a) Cleans own teeth/dentures regularly and independently
	<input type="checkbox"/>	b) Cleans teeth/dentures if given appropriate items
	<input type="checkbox"/>	c) Requires some assistance, toothpaste on brush, brush to mouth etc
	<input type="checkbox"/>	d) Full assistance given
	<input type="checkbox"/>	e) Not applicable
8. BATH/ SHOWER	<input type="checkbox"/>	a) Bathes regularly and independently
	<input type="checkbox"/>	b) Needs bath to be drawn/shower turned on but washes independently
	<input type="checkbox"/>	c) Needs supervision and prompting to wash
	<input type="checkbox"/>	d) Totally dependent, needs full assistance
	<input type="checkbox"/>	e) Not applicable
9. TOILET/ COMMODE	<input type="checkbox"/>	a) Uses toilet appropriately when required
	<input type="checkbox"/>	b) Needs to be taken to the toilet and given assistance
	<input type="checkbox"/>	c) Incontinent of urine or faeces
	<input type="checkbox"/>	d) Incontinent of urine and faeces
	<input type="checkbox"/>	e) Not applicable
10. TRANSFERS	<input type="checkbox"/>	a) Can get in/out of chair unaided
	<input type="checkbox"/>	b) Can get into a chair but needs help to get out
	<input type="checkbox"/>	c) Needs help getting in and out of a chair
	<input type="checkbox"/>	d) Totally dependent on being put into and lifted from chair
	<input type="checkbox"/>	e) Not applicable
11. MOBILITY	<input type="checkbox"/>	a) Walks independently
	<input type="checkbox"/>	b) Walks with assistance i.e. furniture, arm for support
	<input type="checkbox"/>	c) Uses aids to mobilise i.e. frame, sticks etc.
	<input type="checkbox"/>	d) Unable to walk
	<input type="checkbox"/>	e) Not applicable
12. ORIENTATION - TIME	<input type="checkbox"/>	a) Fully orientated to time/day/date etc.
	<input type="checkbox"/>	b) Unaware of time/day etc but seems unconcerned
	<input type="checkbox"/>	c) Repeatedly asks the time/day/date
	<input type="checkbox"/>	d) Mixes up night and day
	<input type="checkbox"/>	e) Not applicable
13. ORIENTATION - SPACE	<input type="checkbox"/>	a) Fully orientated to surroundings
	<input type="checkbox"/>	b) Orientated to familiar surroundings only
	<input type="checkbox"/>	c) Gets lost in home, needs reminding where bathroom is, etc.
	<input type="checkbox"/>	d) Does not recognise home as own and attempts to leave
	<input type="checkbox"/>	e) Not applicable

14. COMMUNICATION	a)	Able to hold appropriate conversation
	b)	Shows understanding and attempts to respond verbally with gestures
	c)	Can make self understood but difficulty understanding others
	d)	Does not respond to, or communicate with others
	e)	Not applicable
15. TELEPHONE	a)	Uses telephone appropriately, including obtaining correct number
	b)	Uses telephone if number given verbally/visually or pre-dialled
	c)	Answers telephone but does not make calls
	d)	Unable/unwilling to use telephone at all
	e)	Not applicable
16. HOUSEWORK / GARDENING	a)	Able to do housework/gardening to previous standard
	b)	Able to do housework/gardening but not to previous standard
	c)	Limited participation with a lot of supervision
	d)	Unwilling/unable to participate in previous activities
	e)	Not applicable
17. SHOPPING	a)	Shops to previous standard
	b)	Only able to shop for 1 or 2 items with or without a list
	c)	Unable to shop alone, but participates when accompanied
	d)	Unable to participate in shopping even when accompanied
	e)	Not applicable
18. FINANCES	a)	Responsible for own finances at previous level
	b)	Unable to write cheque. Can sign name & recognises money values
	c)	Can sign name but unable to recognise money values
	d)	Unable to sign name or recognise money values
	e)	Not applicable
19. GAMES /HOBBIES	a)	Participates in pastimes/activities to previous standard
	b)	Participates but needs instruction/supervision
	c)	Reluctant to join in, very slow needs coaxing
	d)	No longer able or willing to join in
	e)	Not applicable
20. TRANSPORT	a)	Able to drive, cycle or use public transport independently
	b)	Unable to drive but uses public transport or bike etc.
	c)	Unable to use public transport alone
	d)	Unable/unwilling to use transport even when accompanied
	e)	Not applicable

Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley, 1988)

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**
 Circle the "2" if you **Strongly Disagree**
 Circle the "3" if you **Mildly Disagree**
 Circle the "4" if you are **Neutral**
 Circle the "5" if you **Mildly Agree**
 Circle the "6" if you **Strongly Agree**
 Circle the "7" if you **Very Strongly Agree**

- | | | | | | | | |
|---|---|---|---|---|---|---|---|
| 1. There is a special person who is around when I am in need. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2. There is a special person with whom I can share my joys and sorrows. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3. My family really tries to help me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4. I get the emotional help and support I need from my family. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 5. I have a special person who is a real source of comfort to me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 6. My friends really try to help me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 7. I can count on my friends when things go wrong. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 8. I can talk about my problems with my family. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 9. I have friends with whom I can share my joys and sorrows. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 10. There is a special person in my life who cares about my feelings. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 11. My family is willing to help me make decisions. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 12. I can talk about my problems with my friends. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Zarit Burden Interview

Caregiver's name: _____ Date: ____/____/____

INSTRUCTIONS:

The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; **never, rarely, sometimes, quite frequently, or nearly always**. There are no right or wrong answers.

	Never (0)	Rarely (1)	Sometimes (2)	Quite Frequently (3)	Nearly Always (4)
1. Do you feel that your relative asks for more help than he/she needs?					
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?					
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?					
4. Do you feel embarrassed over your relative's behavior?					
5. Do you feel angry when you are around your relative?					
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?					
7. Are you afraid what the future holds for your relative?					
8. Do you feel your relative is dependent upon you?					
9. Do you feel strained when you are around your relative?					
10. Do you feel your health has suffered because of your involvement with your relative?					
11. Do you feel that you don't have as much privacy as you would like, because of your relative?					

	Never (0)	Rarely (1)	Sometimes (2)	Quite Frequently (3)	Nearly Always (4)
12. Do you feel that your social life has suffered because you are caring for your relative?					
13. Do you feel uncomfortable about having friends over, because of your relative?					
14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?					
15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?					
16. Do you feel that you will be unable to take care of your relative much longer?					
17. Do you feel you have lost control of your life since your relative's illness?					
18. Do you wish you could just leave the care of your relative to someone else?					
19. Do you feel uncertain about what to do about your relative?					
20. Do you feel you should be doing more for your relative?					
21. Do you feel you could do a better job in caring for your relative?					

	Not at all (0)	A little (1)	Moderately (2)	Quite a bit (3)	Extremely (4)
22. Overall, how burdened do you feel in caring for your relative?					

Sum (Items 1-22)

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Mood Assessment Scale (GDS)

Caregiver's name: _____ Date: ____ / ____ / ____

1. Are you satisfied with your life?	YES / NO
2. Have you dropped many of your activities and interests?	YES / NO
3. Do you feel that your life is empty?	YES / NO
4. Do you often get bored?	YES / NO
5. Are you hopeful about the future?	YES / NO
6. Are you bothered by thoughts you can't get out of your head?	YES / NO
7. Are you in good spirits most of the time?	YES / NO
8. Are you afraid that something bad is going to happen to you?	YES / NO
9. Do you feel happy most of the time?	YES / NO
10. Do you often feel helpless?	YES / NO
11. Do you often get restless and fidgety?	YES / NO
12. Do you prefer to stay at home, rather than going out and doing new things?	YES / NO
13. Do you frequently worry about the future?	YES / NO
14. Do you feel you have more problems with memory than most?	YES / NO
15. Do you think it is wonderful to be alive now?	YES / NO
16. Do you often feel downhearted and blue?	YES / NO
17. Do you feel pretty worthless the way you are now?	YES / NO
18. Do you worry a lot about the past?	YES / NO
19. Do you find life very exciting?	YES / NO
20. Is it hard for you to get started on new projects?	YES / NO

21. Do you feel full of energy?	YES / NO
22. Do you feel that your situation is hopeless?	YES / NO
23. Do you think that most people are better off than you are?	YES / NO
24. Do you frequently get upset over little things?	YES / NO
25. Do you frequently feel like crying?	YES / NO
26. Do you have trouble concentrating?	YES / NO
27. Do you enjoy getting up in the morning?	YES / NO
28. Do you prefer to avoid social gatherings?	YES / NO
29. Is it easy for you to make decisions?	YES / NO
30. Is your mind as clear as it used to be?	YES / NO

Service-Use-Questionnaire

Caregiver's name: _____ Date: ____/____/____

We would like to know how much help the person you care for receives from you, family or friends, and from professional caregivers.

1.1 Has he/she received **HELP FROM YOU**, family or friends?

NO ☐ YES ☐ If YES please specify the type of care and about how long it takes:

Think about a **typical day** (say yesterday). Tick the box (✓) if the patient has required help or supervision in any of these areas. Record about how long is spent on each activity **over 24 hours**.

Type of care provided (Please tick (✓) all that apply and give time spent)	Time spent in a typical day	
	Hours	Minutes
<input type="checkbox"/> Supervising the person (for example, keeping an eye on the person to be sure that they do not wander off or get into some kind of difficulty, looking out for the person, preventing the person from getting lost, finding the person if they get lost)	_____	_____
<input type="checkbox"/> Using Transportation (for example, reminding the person about means of transportation, taking the person to various places (other than shopping) by car or public transport or taxi)	_____	_____
<input type="checkbox"/> Dressing (for example, reminding the person to dress, choosing what to wear, laying out clothes, helping the person to dress or undress, supervising the person dressing, keeping the person from undressing at the wrong time)	_____	_____
<input type="checkbox"/> Eating (for example, reminding the person to eat, setting up utensils and food, cutting or arranging food on the plate, supervising or encouraging the person to eat, cleaning the person after eating)	_____	_____
<input type="checkbox"/> Looking after their appearance (for example, reminding the person to brush their teeth, brush their hair, apply cosmetics, shave or care for nails, helping the person to groom, setting out items for grooming activities, supervising grooming activities, maintaining the person's appearance over the course of the day)	_____	_____

1.2 Does he/she need **constant supervision** during the day? NO ☐ YES ☐

1.3 Does he/she need round the clock (**24 hour**) **supervision** or care? NO ☐ YES ☐

2.1 Has he/she received help from **OUTSIDE CARERS** (e.g. 'Nurse Maude') in the last 2 weeks?

NO ☐ YES ☐ If YES, please say who from and how long each visit took:

Type of service (Please tick (✓) all that apply)	Number of visits in last 2 weeks	Average time spent per visit
<input type="checkbox"/> Visiting Nurse		
<input type="checkbox"/> Support Worker (personal help)		
<input type="checkbox"/> Support Worker (domestic help)		
<input type="checkbox"/> "Meals on Wheels"		
<input type="checkbox"/> Day-Care Service		
<input type="checkbox"/> Others (specify)		

2.2 Have any of these services **STARTED** in the last 3 months?

NO ☐ YES ☐ If YES, please give details: _____

Thank you for your help!

January, week 1 of 4
Person with dementia

Monday, the 02.01.07 — Sunday, the 08.01.07 Participant's number: 480

Consultations with a health professional (GP, nurse, psychiatrist, geriatrist, others) Who did <u>s/he</u> see: <u>Dr. Brown (GP)</u> For how long:hrs. <u>20</u> min Costs (if any): <u>29.00</u> NZ\$ Who did <u>s/he</u> see: <u>Dr. Croucher</u> For how long:hrs.min Costs (if any):NZ\$ Who did <u>s/he</u> see: For how long:hrs.min Costs (if any):NZ\$	One-to-one counselling (social worker, psychologist, Alzheimer's Canterbury) Who did <u>s/he</u> see: <u>Elizabeth (soc. w. Alz. Cont.)</u> For how long:hrs. <u>30</u> min Costs (if any):NZ\$ Who did <u>s/he</u> see: For how long:hrs.min Costs (if any):NZ\$ Who did <u>s/he</u> see: For how long:hrs.min Costs (if any):NZ\$
Medicines for the person with dementia Did you pay for any of the following drugs? <input type="checkbox"/> Aricept (Donepezil) <input type="checkbox"/> Reminyl (Galantamine) <input type="checkbox"/> Exelon (Rivastigmine) <input checked="" type="checkbox"/> Ebixa (Memantine) List any other mental health medicines which you bought from your chemist this week:	Group meetings ("Memory Group", others) Which meeting did <u>s/he</u> attend: <u>Memory Group</u> For how long:hrs. <u>40</u> min Costs (if any):NZ\$ Which meeting did <u>s/he</u> attend: For how long:hrs.min Costs (if any):NZ\$
Days in hospital/ Emergency department (overnight stays!) Number: <u>2</u> nights Reason: <u>Dad fell and broke his right arm.</u>	Other costs What for: <u>annual membership</u> <u>Alab. Canterbury</u> Costs: <u>30.00</u> NZ\$

Any questions? Please call Franziska at 3642 987 ext.8362 or Philippa (admin.) at 366 7001 ext.8691.

Caregiver

Consultations with a health professional (GP, nurse, psychiatrist, geriatrist...) Who did <u>you</u> see: For how long:hrs.min Costs (if any):NZ\$ Who did <u>you</u> see: For how long:hrs.min Costs (if any):NZ\$ Who did <u>you</u> see: For how long:hrs.min Costs (if any):NZ\$	One-to-one counselling (social worker, psychologist, Alzheimer's Canterbury) Who did <u>you</u> see: For how long:hrs.min Costs (if any):NZ\$ Who did <u>you</u> see: For how long:hrs.min Costs (if any):NZ\$ Who did <u>you</u> see: For how long:hrs.min Costs (if any):NZ\$
Medicines for you List any other mental health medicines you bought from your chemist this week:	Group meetings ("Carers' Group"...) Which meeting did <u>you</u> attend: For how long:hrs.min Costs (if any):NZ\$ Which meeting did <u>you</u> attend: For how long:hrs.min Costs (if any):NZ\$
Days of work loss due to care (if you are not retired) Number:days Reason:	
Days in hospital/ Emergency department (overnight stays!) Number:nights Reason:	Other costs What for: Costs:NZ\$

Any questions? Please call Franziska at 3642 987 ext.8362 or Philippa (admin.) at 366 7001 ext.8691.

Appendix M: Questionnaires added at follow-up assessment

Date: __/__/____Participant number: ____

Caregiver Work Status

1. Since my last visit, have you been working for pay (part or the whole period)?

Yes ☐ If yes, answer question 2.

No ☐ If no, go to the next page.

2. Since the last visit, have you stopped working completely?

Yes ☐ If yes, answer question 5 only.

No ☐ If no, go to question 3.

3. How many hours in total do you work for pay per week?

hours/week

3a. Of this number of hours, are you for some part paid to care for the patient?

Yes ☐ If yes, answer question 3b.

No ☐ If no, go to question 4.

3b. If yes, how many hours per week?

hours/week

4. Since my last visit, have you needed to cut down the number of hours that you work in your regular job because of your caregiving responsibilities?

Yes ☐ If yes, answer question 4a.

No ☐ If no, go to the next page.

4a. If yes, how many hours did you cut down?

hours/week

5. Why did you stop/reduce working?

a. Reached retirement age

b. Early retirement (not related to patient's illness)

c. Laid off

d. Own health problems

e. To care for the patient

f. Other

g. Not applicable

Please see the next page!

1

Economic Questionnaire

1. Since my last visit, did your relative start to take any of the following drugs:

Aricept ☐

Reminyl ☐

Exelon ☐

Ebixa ☐

Any other mental health medication: _____ (details)

If YES, how much do you pay for this medication every month? NZ\$ _____

2. Please tick the box that best describes your situation.

	Strongly Agree	Agree	Disagree	Strongly Disagree
a. I feel that caring for my relative is causing me to dip into savings meant for other things.				
b. I feel that my family and I must give up necessities because of the expense to care for my relative.				
c. I feel that my family and I cannot afford those little extras because of the expense to care for my relative.				
d. I feel that caring for my relative is too expensive.				

3. Do you think financial assistance would help you to fulfil your role as a caregiver (enabling your relative to live at home as long as possible)?

a. Yes ☐

b. No ☐

Please see the next page!

2

Caregiving during the past 12 months

1. In the past 12 months, was there a period that was very difficult for you?

a. Yes ☐

b. No ☐

If yes: please indicate (by ticking the box) which month(s) was/were very difficult and how much you were struggling during this time to care for your relative.

Month	✓	A little	Moderately	Quite a bit	Extreme
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					

2. What made this the worst period in the past 12 months?

Please see the next page!

3. In the past 12 months, was there a period that was easier for you than other times?

a. Yes ☐

b. No ☐

If yes: please indicate (by ticking the box) which month(s) was/were easier and how you rate your ability to care for your relative during this time.

Month	✓	Poor	Fair	Good	Excellent
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					

4. What made this period easier than other times in the past 12 months?

Thank you!

Questionnaire for TeleMessenger

This questionnaire will help us to evaluate the automated phone calls you received monthly.

1. What is your age? Please circle.

0-35 36-45 46-55 55+ years of age

2. What is your sex? Please tick the box. Male ☐ Female ☐

3. Do you have a mobile phone? Please tick the box. Yes ☐ No ☐

4. How effective were the monthly automated phone calls at reminding you of sending in the diary? Please rate 1-5 by ticking one of the boxes.

1 = Totally ineffective ☐

2 = Slightly ineffective ☐

3 = Effective ☐

4 = Very effective ☐

5 = Extremely effective ☐

5. How effective were the automated phone calls at reminding you compared to a real person calling you? Please rate 1-5 by ticking one of the boxes.

1 = A lot less effective ☐

2 = Slightly less effective ☐

3 = About the same ☐

4 = Slightly more effective ☐

5 = A lot more effective ☐

6. If you had to choose between an automated reminder call or a real person calling you which option would you choose? Please indicate by ticking one of the boxes.

1 = Automated call ☐

2 = Real person ☐

3 = No preference ☐

Please see next page!

7. What do you think of the computer voice? Please give details.

8. Did the calls become tiresome in any way? Please give details.

9. How could the reminder calls be improved? Please give details.

10.1 Please answer this question only if you have a mobile phone:

Would a text message (SMS) be more or less effective for you to be reminded – compared to a call? Please tick one of the boxes.

Yes, a SMS would be more effective than a reminder call ☐

No, a SMS would *not* be more effective than a reminder call ☐

10.2 Why would a SMS be more effective or less effective than a phone call? Please give details.

Thank you!

Appendix N: Questionnaires administered to participants who discontinued because PWD had moved into residential care

Date: __ __ / __ __ / __ __

Participant number: __ __

Person with Dementia (patient) Living Accommodation

1. Since my last visit, your relative has permanently changed his/her living accommodation. Please specify his/her current living accommodation.
 - a. Long term residential care (rest home etc., not dementia-specific)
 - b. Long term residential care (rest home etc., dementia-specific)
 - c. Long term institutional care (public or private hospital)
 - d. Other_____ (please specify)
2. Please specify the date at which the change occurred.
__ __ / __ __ / __ __
3. Please specify the principal reason for this change in living accommodation.
 - a. Worsening of patient's cognitive functioning
 - b. Worsening of patient's ability to perform daily tasks (e.g., feeding, dressing, housekeeping, etc.)
 - c. Increase in patient's behavioural problems (e.g., apathy, irritability, depression, etc.)
 - d. Poor caregiver health
 - e. Other_____ (please specify)

Please see the next page!

Caregiver Work Status

1. Since my last visit, have you been working for pay (part or the whole period)?
Yes ☐ If yes, answer question 2.
No ☐ If no, go to the next page.
2. Since the last visit, have you stopped working completely?
Yes ☐ If yes, answer question 5 only.
No ☐ If no, go to question 3.
3. How many hours in total do you work for pay per week?
 hours/week
- 3a. Of this number of hours, are you for some part paid to care for the patient?
Yes ☐ If yes, answer question 3b.
No ☐ If no, go to question 4.
- 3b. If yes, how many hours per week?
 hours/week
4. Since my last visit, have you needed to cut down the number of hours that you work in your regular job because of your caregiving responsibilities?
Yes ☐ If yes, answer question 4a.
No ☐ If no, go to the next page.
- 4a. If yes, how many hours did you cut down?
 hours/week
5. Why did you stop/reduce working?
- | | |
|--|--------------------------|
| a. Reached retirement age | <input type="checkbox"/> |
| b. Early retirement (not related to patient's illness) | <input type="checkbox"/> |
| c. Laid off | <input type="checkbox"/> |
| d. Own health problems | <input type="checkbox"/> |
| e. To care for the patient | <input type="checkbox"/> |
| f. Other | <input type="checkbox"/> |
| g. Not applicable | <input type="checkbox"/> |

Please see the next page!

Economic Questionnaire

1. Since my last visit, did the patient start to take any of the following drugs:
- Aricept ☐
- Reminyl ☐
- Exelon ☐
- Ebixa ☐
- Any other mental health medication: _____ (details)
- If YES, how much do you pay for this medication every month? NZ\$ _____
2. Please tick the box that best describes your situation.
- | | Strongly Agree | Agree | Disagree | Strongly Disagree |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| a. I feel that caring for my relative is causing me to dip into savings meant for other things. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. I feel that my family and I must give up necessities because of the expense to care for my relative. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. I feel that my family and I cannot afford those little extras because of the expense to care for my relative. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. I feel that caring for my relative is too expensive. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
3. Do you think financial assistance would have helped you to fulfil your role as a caregiver (enabling the patient to live at home for longer)?
- a. Yes ☐
- b. No ☐

Please see the next page!

Caregiving during the past 12 months

1. In the months between my visit and the patient's change into residential care, was there a period that was very difficult for you?
- a. Yes ☐
- b. No ☐

If yes: please indicate (by ticking the box) which month(s) was/were very difficult and how much you were struggling during this time to care for your relative.

Month	✓	A little	Moderately	Quite a bit	Extreme
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					

2. What made this the worst period in the past 12 months?

Please see the next page!

3. In the months between my visit and the patient's change into residential care, was there a period that was easier for you than other times?

- a. Yes ☐
- b. No ☐

If yes: please indicate (by ticking the box) which month(s) was/were easier and how you rate your ability to care for your relative during this time.

Month	✓	Poor	Fair	Good	Excellent
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					

4. What made this period easier than other times in the past 12 months?

Thank you!

Questionnaire for TeleMessenger

This questionnaire will help us to evaluate the automated phone calls you received monthly.

1. What is your age? Please circle.

0-35 36-45 46-55 55+ years of age

2. What is your sex? Please tick the box. Male ☐ Female ☐

3. Do you have a mobile phone? Please tick the box. Yes ☐ No ☐

4. How effective were the monthly automated phone calls at reminding you of sending in the diary? Please rate 1-5 by ticking one of the boxes.

1 = Totally ineffective ☐

2 = Slightly ineffective ☐

3 = Effective ☐

4 = Very effective ☐

5 = Extremely effective ☐

5. How effective were the automated phone calls at reminding you compared to a real person calling you? Please rate 1-5 by ticking one of the boxes.

1 = A lot less effective ☐

2 = Slightly less effective ☐

3 = About the same ☐

4 = Slightly more effective ☐

5 = A lot more effective ☐

6. If you had to choose between an automated reminder call or a real person calling you which option would you choose? Please indicate by ticking one of the boxes.

1 = Automated call ☐

2 = Real person ☐

3 = No preference ☐

Please see next page!

7. What do you think of the computer voice? Please give details.

8. Did the calls become tiresome in any way? Please give details.

9. How could the reminder calls be improved? Please give details.

10.1 Please answer this question only if you have a mobile phone:

Would a text message (SMS) be more or less effective for you to be reminded – compared to a call? Please tick one of the boxes.

Yes, a SMS would be more effective than a reminder call ☐

No, a SMS would *not* be more effective than a reminder call ☐

10.2 Why would a SMS be more effective or less effective than a phone call? Please give details.

Thank you!

Appendix O: Information letter with baseline results for participants

Dear participants,

Thank you for taking part in the study "Quality of life of persons with dementia and their families". More than 100 people helped us to gain better understanding of factors that might help you in your current situation. These findings are most important not only for us and the team at The Princess Margaret Hospital, but also for the Ministry of Health. We are hoping that the results will help to secure funding for interventions like day care, respite care and medication. Publishing these findings allows us for the first time to compare the NZ situation with countries from all over the world and to benefit from each other's experiences.

The following is a short summary of our findings after analyzing the data collected during the first year interviews (baseline).

Results:

At baseline 53 patient/caregiver dyads were included. Patients' quality of life (QoL) was strongly correlated with behavioural problems and caregivers' QoL. Patients' QoL was also negatively associated with their daily functioning, CDR (stage of illness), and carers' burden. Symptoms of depression in patients were (negatively) correlated with their QoL and carers' burden. Difficult behaviours showed association with depression in patients, and carers' burden and QoL. Increased informal care negatively impacts on burden and depression in caregivers. Depression and neuropsychological behaviours in patients increase the level of informal care. Joint income/pension and financial burden of care are negatively correlated with carers' QoL, depression, and burden. The level of cognitive impairment and the level of formal support are not associated with patients' or caregivers' QoL.

Conclusion:

Depression in patients and caregivers, each other's quality of life, patients' behavior and functioning, as well as caregivers' burden, and the level of informal care can predict quality of life in dementia. Reducing the intensity of informal care - by treating depression and difficult behaviors in patients - might reduce caregivers' depressive symptoms and burden. Developing a financial scheme that rewards informal caregivers for their time spent caring could be a key factor in supporting informal caregivers in their role and therefore delaying institutionalization.

Again, this study was only possible because of your time and involvement. We would like to thank each of you for the diverse contributions, perspectives and the serious and thoughtful participation you brought to this project. You will receive a letter with the final results (follow-up) and an invitation for a presentation of these findings in September 2009.

With warm regards,

Franziska Gallrach,

Dr. Ray Kirk, Prof. Andrew Hornblow and Dr. Matthew Croucher

Appendix P: Information letter with baseline results for participants who discontinued because the PWD had passed away

Christchurch, 06.03.2009

Dear M [REDACTED]

I was saddened to hear the news about the death of [REDACTED] y thoughts are with you and your loved ones during this difficult time of loss. I enjoyed getting a chance to meet Lyall during my visit last year. He seemed to be a very loving man. Please let me know if there is anything I can help you with.

I also would like to take the opportunity to thank you for taking part in the study "Quality of life of persons with dementia and their families". More than 100 people helped us to gain better understanding of factors that might help you in your current situation. These findings are most important not only for us and the team at The Princess Margaret Hospital, but also for the Ministry of Health. We are hoping that the results will help to secure funding for interventions like day care, respite care and medication. Publishing these findings allows us for the first time to compare the NZ situation with countries from all over the world and to benefit from each other's experiences.

The following is a short summary of our findings after analyzing the data collected during the first year interviews (baseline).

Results:

At baseline 53 patient/caregiver dyads were included. Patients' quality of life (QoL) was strongly correlated with behavioural problems and caregivers' QoL. Patients' QoL was also negatively associated with their daily functioning, CDR (stage of illness), and carers' burden. Symptoms of depression in patients were negatively correlated with their QoL and carers' burden. Difficult behaviours showed association with depression in patients, and carers' burden, and QoL. Increased informal care negatively impacts on burden and depression in caregivers. Depression and neuropsychological behaviours in patients increase the level of informal care. Joint income/pension and financial burden of care are negatively correlated with carers' QoL, depression and burden. The level of cognitive impairment and the level of formal support are not associated with patients' or caregivers' QoL.

Conclusion:

Depression in patients and caregivers, each other's quality of life, patients' behavior and functioning, as well as caregivers' burden, and the level of informal care can predict quality of life in dementia. Reducing the intensity of informal care - by treating depression and difficult behaviors in patients - might reduce caregivers' depressive symptoms and burden. Developing a financial scheme that rewards informal caregivers for their time spent caring could be a key factor in supporting informal caregivers in their role and therefore delaying institutionalization.

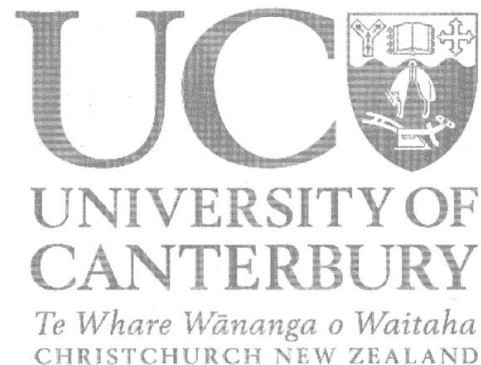
Again, this study was only possible because of your time and involvement. We would like to thank all participants for your diverse contributions, perspectives and the serious and thoughtful involvement you brought to this project.

You will receive a letter with the final results (follow-up) and an invitation for a presentation of these findings in September 2009.

With warm regards,

Franziska Gallrach
Franziska Gallrach,

Dr. Ray Kirk, Prof. Andrew Hornblow and Dr. Matthew Croucher



Appendix Q: Information letter with baseline results for participants who discontinued because the caregiver had passed away

Christchurch, 06.03.2009

Dear Ju [redacted]

I was saddened to hear the news about the death of B [redacted] thoughts are with you and your loved ones during this difficult time of loss. I enjoyed getting a chance to meet Brian during my visit last year. He seemed to be a very loving man. I hope everything is fine with you and that your mum has settled well into her new home. Please let me know if there is anything I can help you with.

I would also like to take the opportunity to thank you for your mum's and dad's participation in the study "Quality of life of persons with dementia and their families". More than 100 people helped us to gain better understanding of factors that might help you in your current situation. These findings are most important not only for us and the team at The Princess Margaret Hospital, but also for the Ministry of Health. We are hoping that the results will help to secure funding for interventions like day care, respite care and medication. Publishing these findings allows us for the first time to compare the NZ situation with countries from all over the world and to benefit from each other's experiences.

The following is a short summary of our findings after analyzing the data collected during the first year interviews (baseline).

Results:

At baseline 53 patient/caregiver dyads were included. Patients' quality of life (QoL) was strongly correlated with behavioural problems and caregivers' QoL. Patients' QoL was also negatively associated with their daily functioning, CDR (stage of illness), and carers' burden. Symptoms of depression in patients were (negatively) correlated with their QoL and carers' burden. Difficult behaviours showed association with depression in patients, and carers' burden and QoL. Increased informal care negatively impacts on burden and depression in caregivers. Depression and neuropsychological behaviours in patients increase the level of informal care. Joint income/pension and financial burden of care are negatively correlated with carers' QoL, depression, and burden. The level of cognitive impairment and the level of formal support are not associated with patients' or caregivers' QoL.

Conclusion:

Depression in patients and caregivers, each other's quality of life, patients' behavior and functioning, as well as caregivers' burden, and the level of informal care can predict quality of life in dementia. Reducing the intensity of informal care - by treating depression and difficult behaviors in patients - might reduce caregivers' depressive symptoms and burden. Developing a financial scheme that rewards informal caregivers for their time spent caring could be a key factor in supporting informal caregivers in their role and therefore delaying institutionalization.

Again, this study was only possible because of your parents' time and involvement. We would like to thank all participants for their diverse contributions, perspectives and the serious and thoughtful involvement they brought to this project.

You will receive a letter with the final results (follow-up) and an invitation for a presentation of these findings in September 2009.

With warm regards,


Franziska Gallrach,

Dr. Ray Kirk, Prof. Andrew Hornblow and Dr. Matthew

Appendix R: Information letter with baseline results for participants who discontinued because the PWD had moved into residential care

Christchurch, 17.06.2009

Dear Nancy Blue

Thank you for taking part in the study "Quality of life of persons with dementia and their families". More than 100 people helped us to gain better understanding of factors that might help you in your current situation. These findings are most important not only for us and the team at The Princess Margaret Hospital, but also for the Ministry of Health. We are hoping that the results will help to secure funding for interventions like day care, respite care and medication. Publishing these findings allows us for the first time to compare the NZ situation with countries from all over the world and to benefit from each other's experiences.

The following is a short summary of our findings after analyzing the data collected during the first year interviews (baseline).

Results:

At baseline 53 patient/caregiver dyads were included. Patients' quality of life (QoL) was strongly correlated with behavioural problems and caregivers' QoL. Patients' QoL was also negatively associated with their daily functioning, CDR (stage of illness), and carers' burden. Symptoms of depression in patients were negatively correlated with their QoL and carers' burden. Difficult behaviours showed association with depression in patients, and carers' burden and QoL. Increased informal care negatively impacts on burden and depression in caregivers. Depression and neuropsychological behaviours in patients increase the level of informal care. Joint income/pension and financial burden of care are negatively correlated with carers' QoL, depression, and burden. The level of cognitive impairment and the level of formal support are not associated with patients' or caregivers' QoL.

Conclusion:

Depression in patients and caregivers, each other's quality of life, patients' behavior and functioning, as well as caregivers' burden, and the level of informal care can predict quality of life in dementia. Reducing the intensity of informal care - by treating depression and difficult behaviors in patients - might reduce caregivers' depressive symptoms and burden. Developing a financial scheme that rewards informal caregivers for their time spent caring could be a key factor in supporting informal caregivers in their role and therefore delaying institutionalization.

Again, this study was only possible because of your time and involvement. We would like to thank each of you for the diverse contributions, perspectives and the serious and thoughtful participation you brought to this project. You will receive a letter with the final results (follow-up) and an invitation for a presentation of these findings in September 2009.

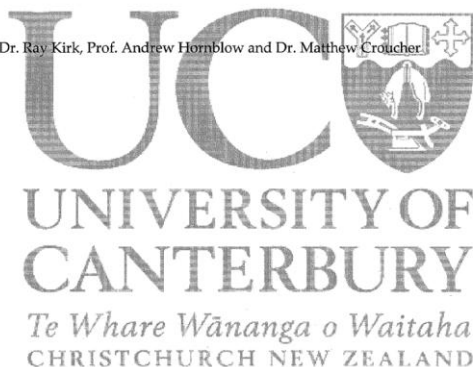
Could you please go through the attached questionnaire and send it back to me using the prepaid envelope enclosed? Thank you very much. I hope everything is fine with you and that Robert has settled well into his/her new home.

With warm regards,

Franziska Gallrach

Franziska Gallrach,

Dr. Ray Kirk, Prof. Andrew Hornblow and Dr. Matthew Croucher



Appendix S: Progress reports and approval Upper South A Regional Ethics Committee September 2008

ETHICS COMMITTEE REPORT FORM

Principal Investigator:	Study Title:	
Franziska Gallrach	Early intervention and quality of life of people with dementia and their family-caregivers living in New Zealand	
Ethics Reference No: URA/07/06/044	Report received:	

Is the study still in progress?	YES	Comments If yes, estimated date of conclusion: August 2009
When did the study commence? If it hasn't, please give reasons & anticipated date:	September 2007	
Have there been any changes/additions to the investigators? If YES, please detail:	NO	
Intended number of participants as stated on the application:	100 patients and their caregivers	
Number of participants recruited at report date:	53 patients and their caregivers	
Are participants still being recruited? <i>If yes, attach the information sheet in use</i>	NO	
Number of participants for whom research is completed at report date:	zero	Baseline interviews are completed for all participants, follow-up starts now
Have any participants withdrawn? If YES how many? How many were a result of: 1. Participant's request; 2. Researcher's decision, eg clinical, non compliance – please specify 3. other (please specify, eg participant left, died etc)	YES: five 1. zero 2. 3 3. 3	2. change into permanent care 3. died
If there has been a change in the number of anticipated participants, will this adversely affect the research?	NO	Conclusions regarding the impact on quality of life depending on the kind of dementia will be limited.
Have there been any changes to the way the study is carried out which have not already been advised to the Committee? If YES, please detail:	NO	
Have there been any ethical or other problems relating to the study? If YES, please outline:	NO	

URA/07/06/044_progressreport_24.09.2008

ANY OTHER COMMENTS: *(use additional pages if necessary)*
(If estimated date of conclusion has changed or study has been terminated before completion, please explain, e.g. recruitment slower than anticipated and why)

//

Have any preliminary or final results from the study been presented? Please give details and provide a summary or abstract. If study is completed and there are no plans for publication, please explain.

Preliminary findings were presented at the University of Canterbury Show Case Postgraduate conference 10.09.08. A second short presentation was given to the involved clinicians at The Princess Margaret Hospital (TPMH) 18.09.08. A further presentation is planned and applied for during the 24th 'Alzheimer's Disease International' 2009 conference in Singapore in March 2009.

Objectives:

The purpose of this study is to measure the quality of life (QoL) of persons with dementia and of their informal family-caregivers. In addition, the study aims to find out what interventions from primary and secondary care are helpful for enhancing QoL, and what these interventions cost.

Methods:

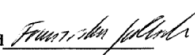
Subjects are 53 patients, recently diagnosed dementia (any type and severity) who live at home, and their primary caregivers. Measurements at baseline and 12 months follow-up include a patient and caregiver rating of the patient's QoL, using a dementia specific QoL-questionnaire. Patients' behavioural symptoms, cognitive status, depressive symptoms and daily functioning are assessed. Caregivers' QoL, their subjective burden, symptoms of depression, perceived level of social support as well as the time they spend on caring for the patient are measured. In addition both direct and indirect costs are estimated. Interventions on a social, educational, psychological, and/or medical level are measured in hours by providing caregivers with a diary to record the amount and kind of intervention. Some direct and indirect costs are also recorded in a diary by the caregivers for the duration of 12 months.

First Findings:

The further developed the disease the more diminished is the patient's QoL and functioning. Patients' QoL is also negatively related with their behavioural symptoms and their level of daily functioning. The prevalence of psychological behaviours increases the patient's risk to develop a depression and caregivers will experience a higher level of burden. The caregivers' rating of the patients' QoL is influenced by the prevalence of difficult behaviours in the patient, a lower level of patients' daily functioning, as well as their own perceived QoL and burden. The level of cognitive impairment and the level of informal support from family and friends seem to have no impact on the patients' or caregivers' overall QoL.

DECLARATION:

I, Franziska Gallrach (Principal Investigator) declare that this is a true and accurate record of my research project as at 24.09.2008.

Signed 

If this study has more than one site, either provide a report for each site and forward them all together or detail the individual site information on this form.

TPMH has provided the principal investigator so far with contact details of eligible, potential participants. From now on TPMH will not be further involved in the study but for discussion and dissemination of the findings.

**Health
and
Disability
Ethics
Committees**

23 October 2008

Ms Franziska Gallrach
98a Perry Street
Papanui
Christchurch 8053

Upper South A Regional Ethics Committee

Ministry of Health
4th Floor, 260 Oxford Tce
PO Box 3877
Christchurch
Phone (03) 372 3037
Fax (03) 372 1015

Email: uppersouth_ethicscommittee@moh.govt.nz

Dear Franziska Gallrach,

Early intervention and quality of life of people with dementia and their family-caregivers living in New Zealand
Investigator: Ms F Gallrach
Locality: The Princess Margaret Hospital
Ethics ref: URA/07/06/044

Thank you for the progress report for the above study, which was considered by the Upper South A Regional Ethics Committee at its meeting on 20 October 2008.

The committee wishes to pass on the following comment:
"Thank you for your progress report and preliminary findings, which are most interesting."

Ethical approval is confirmed for a further 12 months from the report due date. We look forward to receiving another report from you in September 2009.

Yours sincerely



Aleke Dierckx
Upper South A Ethics Committee Administrator
Aleke_dierckx@moh.govt.nz

Appendix T: Progress reports and approval Upper South A Regional Ethics Committee in September 2009

UPPER SOUTH A REGIONAL ETHICS COMMITTEE REPORT FORM

Principal Investigator:	Study Title:
Ms Franziska Gallrach University of Canterbury 98a Perry Street Papanui Christchurch 8053	Early intervention and quality of life of people with dementia and their family-caregivers living in New Zealand
Ethics Reference No: URA/07/06/044	Report received:

		Comments
Is the study still in progress? (including follow up and data analysis)	YES	Follow-up will be finished 28.08.2009. Data analysis is still in progress.
If yes, what is the estimated conclusion date?	Dec. 2009	
When did the study commence? If it hasn't, please give reasons & anticipated date:	September 2007	
Have there been any changes/additions to the investigators? If YES, please detail:	NO	
Intended number of participants as stated on the application:	100 patients and their caregivers	
Number of participants recruited at report date:	53 patients and their caregivers	
Are participants still being recruited? If yes, attach the information sheet in use	NO	
Number of participants for whom research is completed at report date:	50 dyads	Baseline interviews are completed for all participants, 3 follow-up interviews will still be conducted until 28.08.2009.
Have any participants withdrawn? If YES how many? How many were a result of: 1. Participant's request; 2. Researcher's decision, eg clinical, non compliance – please specify 3. other (please specify, eg participant left, died etc)	YES: 19 1. 1 2. 12 3. 6	2. change into permanent care 3. 3 patients and 3 caregivers died
If there has been a change in the number of anticipated participants, will this adversely affect the research?	NO	Conclusions regarding the best intervention depending on stage and kind of dementia will be limited.
Have there been any changes to the way the study is carried out which have not already been advised to the Committee? If YES, please detail:	NO	
Have there been any ethical or other problems relating to the study? If YES, please outline:	NO	

URA/07/06/progressreport_24.08.2009

ANY OTHER COMMENTS: (use additional pages if necessary): NO

Have any preliminary or final results from the study been presented? Please give details and provide a summary or abstract. If study is completed and there are no plans for publication, please explain.

Preliminary findings were presented at the University of Canterbury Show Case Postgraduate conference 10.09.08 (oral presentation) and will be presented again 02.09.2009 (poster). A second short presentation was given to the involved clinicians at The Princess Margaret Hospital (TPMH) 18.09.08.

Baseline findings and preliminary follow-up results were also presented at the following conferences:

1. The 24th 'Alzheimer's Disease International' 2009 conference in Singapore in March 2009 (poster)
2. The 19th World Congress of Gerontology and Geriatrics 2009 in Paris in July 2009 (poster)
3. The 12th International Conference on Alzheimer's Disease in Vienna (oral presentation)

Resulting in the following publications (please see attachment):

Gallrach, F., Kirk, R., Hornblow, A., & Croucher, M. (2009a). Quality of life in dementia: clinical and economic findings from New Zealand. *The Journal of Nutrition, Health and Aging*, 13(Suppl 1), S229

Gallrach, F., Kirk, R., Hornblow, A., & Croucher, M. (2009b). Quality of life in dementia: money matters. *Alzheimer's and Dementia*, 5(4 Suppl 1), S91

Presentations are also planned to be given to the Psychiatry Service for the Elderly staff 25.11.2009 and at the Faculty of Old Age Psychiatrists in Hamilton 30.10.2009, as well as to the study participants at the University of Canterbury 11.09.2009.

DECLARATION:

I, Franziska Gallrach (Principal Investigator) declare that this is a true and accurate record of my research project as at 24.09.2008 (date).

Signed 

If this study has more than one site, either provide a report for each site and forward them all together or detail the individual site information on this form.

TPMH has provided the principal investigator so far with contact details of eligible, potential participants. From now on TPMH will not be further involved in the study but for discussion and dissemination of the findings.

Appendix U: Invitation for a presentation of the study's findings at the University of Canterbury sent out to all participants

Health Sciences Centre

Associate Professor Ray Kirk
Director, Health Sciences Centre
Director, Health Services Assessment Collaboration (HSAC)
Tel +64 3 364 2987 ext. 3108, Fax +64 3 364 3318,
Email: ray.kirk@canterbury.ac.nz



Derek Brown
25 Warren Street
Hillmorton
Christchurch 8025

Christchurch, Tuesday, 8 September 2009

Dear participants and families,

Hereby we would like to thank you again for taking part in the study "Quality of life of persons with dementia and their families" and invite you to attend a presentation of the study's overall findings at the University of Canterbury.

Where: The University of Canterbury, Dovedale Campus (former Teachers' College)
Building: Wheki
Room: 150 (right hand side ground floor)
When: Friday, 11. September 2009, 5pm

This will be a late afternoon tea with coffee, tea and cake giving you the opportunity to get to know some of your fellow participants as well as to ask questions regarding this study, its findings and dementia in general.

You are welcome to invite another family member or close friend who might be interested in this presentation. ***Please make sure to call Franziska Gallrach to confirm your participation and the number of people planning to attend!***

Phone: (03) 3 66 7001 ext.: 8362 (here you can also leave a message for Franziska) or
Mobile: 021 12 86 132

We are looking forward to sharing our knowledge and thoughts with you.

Warm regards,

Franziska Gallrach,

Dr. Ray Kirk, Prof. Andrew Hornblow and Dr. Matthew Croucher

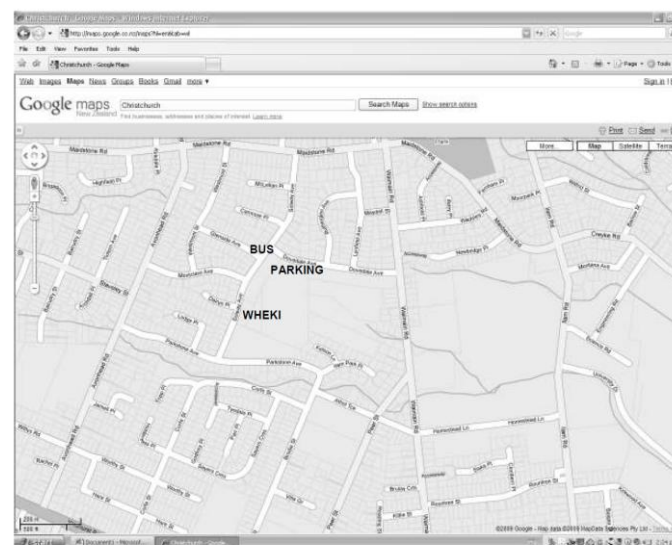
Directions

If you come by car:

- Wheki building is at the College of Education campus, the former Teachers' College (not the main University of Canterbury campus)
- turn off Waimairi Rd into Dovedale Av where you will find plenty of free parking on a Friday afternoon

If you come by bus:

- Bus line 21 (Ilam/ Mt Pleasant) stops right on Dovedale Av
- Stop = "College of Education"



Please turn.

Map of the College of Education campus

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Appendix V: Email communication with PHARMAC regarding funding of dementia medication

To: 'webmaster@pharmac.govt.nz'

Cc: Ray and Andrew

Date: 05.12.2008

To whom it may concern,

My name is Franziska Gallrach. I am a PhD student in Health Sciences at the University of Canterbury. My supervisors are Assoc Prof Ray Kirk and Prof Andrew Hornblow CNZM. My study looks into clinical and economic predictors of quality of life in dementia.

For some background information it would be helpful for me to know what policies PHARMAC is following regarding dementia treatments, acetylcholinesterase inhibitors in particular. I did read through all PTCA meeting notes from your website regarding that matter. The most recent one from 23./24.May 2008 states that *"the Committee recommended that acetylcholinesterase inhibitors be listed in the Pharmaceutical Schedule under the proposed Special Authority criteria with a low priority"*.

Could you please explain to me what that exactly means, "with low priority"? Does that mean these drugs can be prescribed but will not be subsidised? If that is the case I am not sure I understand the reasons for that decision. Countries like Germany, Sweden, the UK, Australia and even the USA all subsidise dementia drugs, even if strict conditions for prescription are applied.

I appreciate your time and effort.

Regards,

Franziska Gallrach

Ph.D.-Candidate (Health Sciences), MA, BA
Health Sciences Centre
University of Canterbury
Private Bag 4800
Christchurch, NEW ZEALAND
Telephone: +64 (0)3-366 7001 ext.8362
Mobile: 021 128 6132
Email: FranziskaGallrach@web.de or franziska.gallrach@canterbury.ac.nz

8 December 2008

Level 9, Cigna House,
40 Mercer Street, PO Box 10-254,
Wellington 6143, New Zealand
Phone 64-4-460-4990
Fax 64-4-460-4995
www.pharmac.govt.nz

Franziska Gallrach
By email: franziska.gallrach@canterbury.ac.nz

Dear Franziska

Acetylcholinesterase inhibitors for dementia

Thank you for your email of 5 December in which you ask us to clarify the meaning of a 'low priority' funding recommendation from PTAC and ask why this is the case for dementia treatments.

How we make funding decisions

PHARMAC uses 9 decision criteria when determining whether or not to subsidise a medicine from within our fixed budget. You may already be aware of it, but I will provide a link to our website where you can review our funding process and see those decision criteria: <http://www.pharmac.govt.nz/patients/DecisionMakingProcess>.

The first step in PHARMAC's funding process is to take advice from our advisory committee, the Pharmacology and Therapeutics Advisory Committee (PTAC), which makes recommendations to PHARMAC. PTAC generally recommends that medicines receive either a low, medium or high priority for funding (if it makes a recommendation to fund) and this recommendation is taken into consideration when we look at which medicines can subsidise next. PTAC may also recommend that an application to fund a particular medicine be declined (as was the case with memantine).

It is important to understand that a positive recommendation from PTAC is just the first step in determining from a large set of funding applications for treatments for various diseases which ones to select and progress towards funding decisions, and neither guarantees selection nor funding. We have to make difficult choices regarding the next best spend of any available funds, and potential opportunity costs, in order to obtain the best health outcomes for all New Zealanders from within the funding provided.

Assessment of funding for a new medicine involves a number of steps, including determining the amount of benefit that is able to be gained from a particular medicine, versus the cost of that medicine. The amount of funding available for spending on pharmaceuticals in New Zealand is limited (as we have a fixed budget), so we have to be very sure that that spending on donepezil, or any other medicine, would be the best health investment on behalf of all New Zealanders.

Acetylcholinesterase inhibitors

In 2004, PHARMAC's Board resolved not to fund donepezil, rivastigmine and galantamine. I have attached a copy of the consultation letter from this time, which explains some of the rationale behind this decision.

A decline from PHARMAC's Board does not necessarily mean that a medicine will never be funded, but it does mean that significant new information would need to be presented to PHARMAC in order for funding to be reconsidered. This could be in the form of price

changes or new clinical information. We periodically review the funding status of unsubsidised medications with this in mind, as happened in February and May this year.

The funding of acetylcholinesterase inhibitors is not currently a priority for PHARMAC funding relative to other funding proposals, taking into account the large budget impact, limited efficacy and poor cost effectiveness of these agents. PTAC's recent recommendation for funding with a low priority is similar to the recommendation that it made when the Board declined funding in 2004. This means that there has been no substantive change in the information already considered by the Board; therefore, the funding status of acetylcholinesterase inhibitors is essentially unchanged. We will ensure to keep all interested parties informed of any developments regarding the funding of acetylcholinesterase inhibitors.

Comparisons with overseas health systems

Our budget focus (in that we have a fixed budget that we must adhere to) is one of the most significant differences in the funding environment in New Zealand compared to other countries. It is one of the reasons why we do make different funding decisions in New Zealand. So, while it is interesting to note what other countries decide to fund, we cannot base our decisions on what other countries decide that they can afford to pay.

I hope that this information has proved helpful for your research. Please feel contact me on (04) 916-7514 if you have any further questions.

Yours sincerely



Geraldine MacGibbon
Therapeutic Group Manager

OCTOBER 2003 CONSULTATION LETTER

14 October 2003

By facsimile

To: Pharmaceutical Suppliers and other interested parties.

Declining applications for the listing of various acetylcholinesterase inhibitors on the Pharmaceutical Schedule

PHARMAC has received submissions to list the following acetylcholinesterase inhibitors in Section B of the Pharmaceutical Schedule:

Chemical	Brand	Supplier	Strength/Presentation
Donepezil	Aricept	Pfizer	5 mg and 10 mg tablets
Galantamine	Reminyl	Janssen Cilag	4, 8 and 12 mg tablets
Rivastigmine	Exelon	Novartis	1.5, 3.0, 4.5 and 6.0 mg capsules

PHARMAC has undertaken extensive assessment of the benefits, costs and cost-effectiveness of these medicines.

PTAC (Pharmacology and Therapeutics Advisory Committee), and the Neurological Subcommittee have evaluated these submissions on several occasions between 1998 and 2003. In summary PTAC advised that:

- the evidence available showed that these products had a limited benefit for a small proportion of patients and for a limited duration;
- there was little evidence to suggest that there were significant differences in effectiveness or tolerability between the three products; and
- acetylcholinesterase inhibitors should be assigned a low priority for listing based on current evidence, having regard to their relatively high cost.

In 2003 PHARMAC completed an economic analysis on acetylcholinesterase inhibitors as part of the prioritisation process. The results of the analysis indicated that these medicines are not good value for money compared with other pharmaceuticals that could be funded.

These medicines are not, therefore, considered to be a high priority for investment compared to other pharmaceuticals awaiting funding.

PHARMAC has also been working on the development of a pilot project to test whether it would be possible to manage entry and exit criteria to these medicines for people with Alzheimer's disease in order to target treatment to the small group of patients who may benefit from treatment. In developing

the pilot project PHARMAC sought advice from PTAC, who considered that the exit criteria would be very difficult, if not impossible, to enforce.

Given the nature of the disease, and number of patients who may desire access to the medicines, a pilot would create inequalities. It would be inevitable that some patients would be denied entry to the pilot due to limited numbers, and that some would be required to stop therapy. Additionally the longer-term expectations of a pilot programme would be for access to be expanded, however, the pilot would not address the key concerns relating to full-scale funding of these medicines.

PHARMAC staff propose to recommend to the PHARMAC Board in October 2003, that these applications, and the pilot project be declined.

This letter serves as formal notification of that intention so that you may provide comment for consideration by the PHARMAC Board. If you would like to provide any comments on this proposal for consideration by the Board, please forward them to Steffan Crausaz (Therapeutic Group Manager) at PHARMAC by 12 pm Friday, 14 November 2003.

Should the PHARMAC Board decline these applications it would not preclude their inclusion in further contractual arrangements at a future date. Rather, it indicates that PHARMAC is not actively progressing funding for acetylcholinesterase inhibitors at this time.

Yours sincerely

Wayne McNee
Chief Executive